

# National **STROKE** Strategy

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## Foreword

### by Alan Johnson MP

### Secretary of State for Health



Stroke has been described as ‘an earthquake in the brain’. The shockwaves of stroke can leave a lasting and profound impact on how people move, see, speak, feel or understand their world.

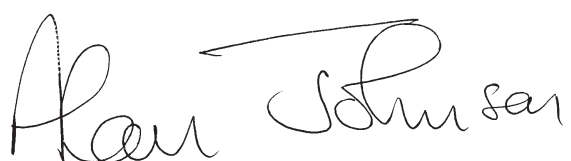
Yet until fairly recently we have as a society been fatalistic or dismissive about all that stroke entails – perhaps ignoring it, perhaps fearing it, but typically regarding it as an inevitability of ageing. Medical and technological advances over the last generation have transformed our understanding of the brain, given us the ability to see what happens when someone experiences a stroke, and developed the treatment possibilities for restoring blood flow and improving brain function when areas of the brain get damaged. We know too that time is critical – the faster someone reaches expert help, the greater their chances of making a full recovery.

These advances present tremendous opportunities for saving lives and reducing disability. Morally, they demand that we treat stroke as the next major challenge for the NHS. Significant improvements have been made over the last decade through the widespread development of stroke units and the growth of dedicated, specialised, multidisciplinary stroke teams. We now need to move from this gradual evolution to a comprehensive revolution. We need to develop the rapid response systems that get people to centres of expertise quickly, directly to the scan they need, and onwards to appropriate treatment and stroke unit care. Working across new stroke networks, we need to commission integrated care that liberates rather than constrains the talents and energies of the doctors, nurses, therapists and their wider teams already working tirelessly to improve services for people who experience stroke.

People struck by stroke often say that the full impact of their condition hits them once they leave hospital and attempt to renegotiate their daily lives. For some, this can feel like a time of abandonment, when it is hard to know how to access help and advice. Yet we know that for months or even years after a stroke, there may be a need for specialised therapeutic help – for example to improve speech or mobility – and that enabling people to participate in work, leisure and education improves well-being, combats depression and often aids recovery. So this strategy is not just about transforming acute care – far from it. The input and commitment of primary care teams, of social care professionals and wider community services is absolutely critical to delivering improved outcomes for people with stroke. And that doesn’t just mean supporting those who have had a stroke, but helping people of all ages establish and maintain a lifestyle that promotes good health and minimises the risk of ever having a stroke.

This strategy sets out what the experts told us should be done to achieve the necessary revolution in stroke care. In some areas, it may seem radical and challenging. This is deliberate and I do not apologise for it. Stroke is this country's third-biggest killer, killing more women than breast cancer. It is the main cause of adult disability, with a devastating impact on hundreds of thousands of people of all ages. Yet it need not be. Many strokes are preventable, most are treatable, and the harm done by stroke can be greatly reduced if we act quickly on important warning signs like transient ischaemic attacks or 'minor strokes', deploy effectively the power of modern imaging, and ensure all patients can benefit from expert, multidisciplinary care.

This strategy presents 20 quality markers outlining the features of a good service, to help commissioners, stroke networks and service providers judge the quality of their local services and plan for the improvements needed. These markers are distilled into a ten-point plan for action to guide those affected by stroke, their carers and the public in looking at the services available locally. Collectively, these markers set an ambitious agenda to deliver world-class stroke services, from prevention right through to life-long support. It will take time to deliver, and stroke networks will need to work with service users to determine the early priorities for their local areas. But there is no excuse for standing still. We can and we must now give stroke the attention it deserves and reduce the individual, family and societal cost of this devastating event.

A handwritten signature in black ink, reading "Alan Johnson". The signature is written in a cursive style with a long horizontal stroke extending from the end of the name.

Alan Johnson MP  
Secretary of State for Health

## Introduction

### by Professor Roger Boyle

### National Director for

### Heart Disease and Stroke



This strategy is the product of a great deal of hard work by many people and I want to pay tribute to all those who have been involved so far.

In particular, I would like to thank the steering group who have led us so well to this point, and all those who were involved in the project groups, who completed detailed work to inform the quality markers.

But lots of other people have been involved too – from coming along to listening events, responding to the consultation, participating in stroke groups across the country and attending seminars. So this strategy represents the views of a great number of people – a significant number of whom have had a stroke themselves.

And I know that a lot of people are already responding to the challenge set out in this strategy. It has been heartening to me as I travel around the country to hear how people are taking stroke seriously and starting the process of change now. What we have done for heart disease, we can now do for stroke.

This strategy therefore marks a point in our journey but we have a long way to go yet, and in many ways it is now that the hard work begins. I look forward to working with you all on taking on and conquering the challenge of stroke.

A handwritten signature in black ink that reads "Roger Boyle". The signature is written in a cursive, flowing style.

Professor Roger Boyle  
National Director for Heart Disease and Stroke

## Executive summary

1. Stroke has a major impact on individual lives and on the nation's health and economy. Strokes are a blood clot or bleed in the brain which can leave lasting damage, affecting mobility, cognition, sight or communication. Stroke, like other vascular diseases such as heart disease, is often preventable, and there are now more treatment options than ever before, with further medical advances likely during the lifespan of this strategy. After stroke, individual recovery can be enhanced through specialist therapy and wider social support.
2. This strategy has been developed by six expert project groups, comprised of representatives from the wide range of professionals who support people with stroke, people who have had a stroke, carers and voluntary associations. It has been further informed and refined through a formal consultation exercise which generated over 1,000 responses, the analysis of which has been published alongside this strategy. It sets a framework of quality markers (QMs) for raising the quality of stroke prevention, treatment, care and support over the next decade.
3. Too few people understand what a stroke is or know to call 999 when symptoms occur. For this reason, the strategy starts with the need for **members of the public and health and social care staff to be able to recognise the main symptoms of stroke and know that it needs to be treated as a medical emergency (QM1)**. Local action to raise awareness will be supported by national awareness-raising activities co-ordinated and funded by the Department of Health (DH).
4. People also need a better understanding of how to reduce their own risk of having a stroke. Risk factors are the same as for other vascular diseases such as heart disease – for example smoking and high blood pressure. The second quality marker looks at **effective assessment and management of vascular risk factors, together with improving information and advice on lifestyle and treatment options (QM2)**.
5. Chapter 1, 'Everyone's challenge: raising awareness and informing and involving', sets out the action needed on public awareness and prevention. It also highlights two themes that run throughout the care pathway: the first is the need to improve **information, advice and support (QM3)** for people who experience stroke; the second is the value of **involving individuals and their carers in developing and monitoring services (QM4)**.
6. Chapter 2, 'Time is brain', sets out the changes needed in the emergency management of transient ischaemic attacks (TIAs) (or minor strokes, explained on page 11) and stroke in order to ensure fewer serious strokes and to improve outcomes for people who experience stroke. Recent evidence shows that TIA needs to be regarded as an emergency and not an elective condition, because the time necessary for effective prevention of a more serious subsequent stroke is extremely short. **High-risk TIA patients need to be assessed by experts and, wherever possible, scanned using**



magnetic resonance imaging (MRI) within 24 hours of experiencing symptoms; lower-risk groups need to be seen within seven days and are given follow-up care (QM5 and QM6). People with suspected stroke should be immediately transferred to a hospital providing hyperacute services throughout the day and night – this includes expert clinical assessment, rapid imaging and the ability to deliver intravenous thrombolysis. They should receive an early multidisciplinary assessment, including swallow screening, and have prompt access to a high-quality stroke unit (QM7, QM8 and QM9). National support will be available to drive improvements to acute care for TIA and stroke, as detailed in Chapter 5.

7. Chapter 3, 'Life after stroke', sets out the care and support needed after stroke, looking at **stroke-specialised rehabilitation (QM10)** within hospital, immediately after transfer to home or care home and for as long as it continues to be of benefit. People with very severe stroke who are not expected to recover should receive **active end of life care (QM11)** from an appropriately skilled workforce, whether in hospital or in the community. Planning for the **transfer of care (QM12)** from hospital to community needs to be improved, working closely with the voluntary sector. **A range of services needs to be locally available to support the individual long-term needs of people who have had a stroke and their carers (QM13)**. After stroke, people need to be offered a **review (QM14)** of their health, social care and secondary prevention needs, typically within six weeks of leaving hospital, before six months have passed and then annually. This will ensure that it is possible to access further specialist advice, information and rehabilitation where needed. Opportunities to **participate in community life and to return to work (QM15 and QM16)** should be provided. National support will be available to drive improvements in community provision for people with stroke, as detailed in Chapter 5.
8. Chapter 4, 'Working together', looks at the workforce and supporting mechanisms needed to drive these improvements across the care pathway. **Stroke networks should be established (QM17)**, bringing together key stakeholders and providers to review, organise and improve delivery of services across the care pathway. These will typically cover a population of between half a million and two million and draw on existing service improvement expertise within cardiac networks. These networks will be supported at a national level.
9. People affected by stroke, and at risk of stroke, should receive care from staff with appropriate **skills, competence and leadership (QM18)**. Local areas will need to **review, plan for and develop (QM19)** a stroke-skilled workforce. DH will support this with leadership training programmes, an increase in the number of stroke physician training places and training packages for specialist nurses and allied health professionals. Additional workforce resources have been made available on the DH stroke website ([www.dh.gov.uk/stroke](http://www.dh.gov.uk/stroke)) to support implementation of the strategy.



10. Chapter 5, 'National support for local implementation', summarises the support available at national level to aid the transformation of stroke care, including initiatives which health services can support that help to minimise the underlying risk factors for stroke and the development of **research and audit (QM20)**. To support improved commissioning of stroke services, DH will be making available an updated version of *Action on Stroke Services: An Evaluation Toolkit* (ASSET). This is an interactive programme enabling local areas to look at the quality of their current provision and establish how making specific improvements will reduce the number of strokes, reduce lengths of hospital stay for stroke, and increase the numbers of people with better outcomes following a stroke.
11. The key features of this comprehensive strategy are summarised in the ten-point plan below. A range of supporting resources are available at [www.dh.gov.uk/stroke](http://www.dh.gov.uk/stroke).

### Ten-point plan for action

1. **Awareness:** what action is your local area taking to improve public and professional awareness of stroke symptoms?
2. **Preventing stroke:** how effectively is your area supporting healthier lifestyles and taking action to tackle vascular risk, for example hypertension, atrial fibrillation and high cholesterol?
3. **Involvement:** are people with stroke informed partners in their care planning? How effectively are those who have had a stroke – including those with communication and/or physical disabilities – involved in planning and evaluating local services?
4. **Acting on the warnings:** TIAs are a clear warning sign that a further stroke may occur and the time window for action is very short – in about half of cases this is a matter of days. Has your local area put in place a system that responds quickly to people who have had a TIA (meaning within 24 hours for the group most at risk of stroke)?
5. **Stroke as a medical emergency:** getting people to the right hospital quickly – where there are specialists who can deliver acute treatments including thrombolysis – will save lives. Is your local stroke network planning to ensure that everyone who could benefit from urgent care is transferred to an acute stroke centre that provides 24-hour access to scans and specialist stroke care?
6. **Stroke unit quality:** stroke unit care is the single biggest factor that can improve a person's outcomes following a stroke. Successful stroke units are built around a stroke-skilled multidisciplinary team that is able to meet the needs of the individuals. How does your local unit rate on the Royal College of Physicians' *National Sentinel Stroke Audit*?

- 7. Rehabilitation and community support:** intensive rehabilitation immediately after stroke, operating across the seven-day week, can limit disability and improve recovery. Specialised rehabilitation needs to continue across the transition to home or care home, ensuring that health, social care and voluntary services together provide the long-term support people need, as well as access to advocacy, care navigation, practical and peer support. Is commissioning and planning integrated across the whole care pathway in your area?
- 8. Participation:** assistance to overcome physical, communication and psychological barriers to engage and participate in community activities helps people to lead more autonomous lives and move on after stroke. This will be across the range of community services – housing, education, leisure, transport, employment – that can help people to participate in community life again. Does your local area consider the needs of people who have had a stroke in accessibility planning?
- 9. Workforce:** people with stroke need to be treated by a skilled and competent workforce. Resources to assist services in planning their workforce requirements are signposted in this strategy. Has your local area undertaken a local needs assessment and developed a workforce action plan?
- 10. Service improvement:** this new vision for stroke care demands services working together in networks, looking across all aspects of the care pathway. Regular local and national audit and increased participation in clinical trials will also drive improvements in stroke care. What are your stroke network's plans for improving stroke care?



# Purpose and scope

## Purpose and scope

The Department of Health (DH) has developed a new national strategy for stroke services in England. The strategy is intended to:

- provide a quality framework against which local services can secure improvements to stroke services and address health inequalities relating to stroke over the next ten years;
- provide advice, guidance and support for commissioners, strategic health authorities, the voluntary sector and social care, in the planning, development and monitoring of services; and
- inform the expectations of those affected by stroke and their families, by providing a guide to high-quality health and social care services.

The strategy does not act as a detailed clinical guideline – the Royal College of Physicians (RCP) guidelines<sup>1</sup> and the forthcoming National Institute for Health and Clinical Excellence (NICE) guidelines fulfil these roles. The strategy does not apply to children's stroke services. Paediatric stroke services are covered by the RCP guidelines.<sup>2</sup>

The strategy applies to stroke services in England only.

## Defining stroke

Stroke is a 'brain attack' caused by a disturbance to the blood supply to the brain. There are two main types of stroke:

- Ischaemic: the most common form of stroke, caused by a clot narrowing or blocking blood vessels so that blood cannot reach the brain, which leads to the death of brain cells due to lack of oxygen.

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<sup>1</sup> Royal College of Physicians, 2004, *National Clinical Guidelines for Stroke*, Second edition, prepared by the Intercollegiate Stroke Working Party, London, RCP

<sup>2</sup> Clinical effectiveness and Evaluation Unit, Royal College of Physicians, 2004, *Stroke in childhood: Clinical guidelines for diagnosis, management and rehabilitation*, prepared by the Paediatric Stroke Working Group

- Haemorrhagic: caused by a bursting of blood vessels producing bleeding into the brain, which causes damage.

Transient ischaemic attacks (TIA), also known as minor strokes, occur when stroke symptoms resolve themselves within 24 hours.

## The impact of stroke

Key data which give a context to the scale of stroke include:<sup>3</sup>

- Every year approximately 110,000 people in England have a stroke.
- Stroke is the third largest cause of death in England: 11 per cent of deaths in England are as a result of stroke. Stroke contributes to the gap in life expectancy between the most deprived areas and the population as a whole.
- 20–30 per cent of people who have a stroke die within a month.
- 25 per cent of strokes occur in people who are under the age of 65.
- There are over 900,000 people living in England who have had a stroke.
- Stroke is the single largest cause of adult disability. 300,000 people in England live with moderate to severe disability as a result of stroke.
- People from certain ethnic minorities are at a higher risk of stroke.

Stroke has a devastating and lasting impact on the lives of people and their families. Individuals often live with the effect for the rest of their lives. A third of people who have a stroke are left with long-term disability.<sup>4</sup> The effects can include aphasia, physical disability, loss of cognitive and communication skills (e.g. leading to aphasia), depression and other mental health problems.

Stroke costs the NHS and the economy about £7 billion a year: £2.8 billion in direct costs to the NHS, £2.4 billion of informal care costs (e.g. the costs of home nursing borne by patients' families) and £1.8 billion in income lost to productivity and disability.<sup>5</sup> Outcomes in the UK compare poorly internationally, despite our services being among the most expensive, with unnecessarily long lengths of stay and high levels of avoidable disability and mortality.<sup>6</sup> We need to redesign services to ensure that we get the best out of the resources we currently use, and this may mean targeted local investment.

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<sup>3</sup> National Audit Office, 2005, *Reducing Brain Damage: Faster access to better stroke care*, London, NAO

<sup>4</sup> Ibid.

<sup>5</sup> Ibid.

<sup>6</sup> Leal J, et al., 'Economic burden of cardiovascular diseases in the enlarged European Union', *European Heart Journal* 27, 1610–1619, 2006

## Developing the strategy

We know that stroke services in England have improved significantly over the last decade, as shown by the findings of the RCP's regular Sentinel Audit. There are already many shining examples of excellent care, some of which were highlighted in the consultation. There is now a consensus in favour of:

- specialist stroke units;
- regarding acute stroke as an emergency;
- rapid access to services for people who have had a TIA;
- immediate access to diagnostic scans and to thrombolysis for patients whose stroke was caused by a clot;
- early supported discharge for people with moderate disability as a result of stroke;
- more emphasis on prevention and public awareness; and
- better support for all people living with stroke in the long term.

However, there is considerable variation in service provision across the country, as highlighted in Lord Darzi's interim report on the NHS Next Stage Review.<sup>7</sup>

Stroke mortality is falling, and at the same time there is a clear desire for more emphasis on prevention and on public awareness. These facts show that improvements are being made. However, there is a need to improve performance overall and to examine the different experiences of other countries to aid the strategy's implementation. The developments we have already seen have taken place against a broad health and social care environment where community services are being refocused and built around the needs of the individual, not the service, promoting independence, well-being and choice. Putting this new evidence into practice requires a reorganisation of the way that all stroke services are delivered. In short, the evidence presents increasing opportunities for transforming the lives of people who are at risk of stroke, or who have had a stroke.

The strategy extends steps taken in recent years to build on and improve stroke services. It was developed by six project groups of independent experts representing a wide range of interested organisations, including voluntary organisations, people who have experienced stroke and their carers. This work was co-ordinated by a steering group chaired by Professor Roger Boyle, the National Director for Heart Disease and Stroke. The emerging recommendations were tested in stakeholder workshops and through two regional listening events.

Between July and October 2007, DH held a public consultation exercise on the draft proposals for the strategy. We received over 1,000 responses from individuals including those who have had a stroke and their carers, and a range of professional and other stakeholder groups. These responses have been analysed and have informed the

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<sup>7</sup> Prof. the Lord Darzi of Denham, 2007, *Our NHS our future: NHS Next Stage Review Interim Report*, DH

development of the final strategy. During the consultation, officials from DH attended a number of stroke-related conferences and meetings across the country to publicise the consultation and gather feedback. We intend to maintain this engagement as the strategy is implemented.

We had an overwhelming response to the consultation from those who have experienced stroke and their carers, with over 800 responses in total from this group. We are grateful in particular to the Stroke Association, Connect and Speakability for their participation in developing the strategy and help in involving so many individuals and carers.

The stroke strategy promotes access to services that is the same for everyone with a need, and there are both policy and legal obligations on DH to consider equality issues when shaping policy. DH has published an Equality Impact Assessment (EIA), which aims to assess whether the strategy will have any adverse effects on any particular group. It also alerts commissioners and service providers of health and social care of the need to monitor the strategy's impact on those groups and to make changes to mitigate any inequality. Service providers and commissioners may need to produce their own EIAs to assess the strategy's impact locally.

The NHS Next Stage Review local clinical pathway group and strategic health authority vision process will examine the changes in stroke services that are needed, and it is already under way, informed by much of the evidence that is set out in this strategy document. We look forward to the development of each strategic health authority's vision for the future of local services across the eight broad pathways of care, and their implications for stroke services.

## How this strategy is structured

Chapters 1 to 4 set out a number of quality markers, which outline the features of a good service. Under each marker is an explanation of why the marker has been set, and a list of the key actions to take for commissioners to meet the standard set out in the marker. Commissioners would be well advised to begin by establishing a baseline, to determine where they already have plans in place and where work is needed. At the end of each marker we suggest some local measures that may help to do this. These are intended to help commissioners to monitor progress in their own areas, not at a national level.

Links to the long-term conditions National Service Framework (NSF)<sup>8</sup> are made in the discussion of each marker because of its focus on improving neurological services for all conditions – from diagnosis to end-of-life care. Commissioners may want to consider how to link the implementation of the stroke strategy to the broader need to deliver the 11 national quality requirements in the NSF.

Chapter 5 sets out the national support for implementation.

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<sup>8</sup> Department of Health, 2005, *The National Service Framework for Long-term Conditions*, London, DH



# Chapter 1

## Everyone's challenge: raising awareness and informing and involving



### Aims

1. To improve public and professional awareness of the risk factors and symptoms of a stroke, and what action to take.
2. To ensure that people who experience a stroke are at the centre of decisions about their treatment and are involved in the design of services.

### Key facts

- The failure to recognise stroke symptoms as a medical emergency – including by NHS Direct and GPs – can mean that urgent medical treatment for stroke is delayed.<sup>9</sup> A MORI poll commissioned by the Stroke Association in 2005 suggested that only half of people asked can correctly identify what a stroke is, with only 40 per cent correctly naming three stroke symptoms, and a quarter did not believe that any specialised treatment or care could make a difference.<sup>10</sup> Sixty per cent would contact their GP or NHS Direct, and only a third of respondents would call an ambulance or go to hospital.<sup>11</sup>
- Nearly one in five GPs said they do not refer around a fifth of cases of a transient ischaemic attack (TIA) or stroke. Just over half of GPs said they would refer someone with a suspected stroke immediately.<sup>12</sup>
- People who are economically disadvantaged have a higher rate of stroke, as well as heart disease and other related diseases.
- People of African or Caribbean ethnicity are at higher risk of having a stroke. Incidence rates, adjusted for age and sex, are twice as high in black people as for white people.<sup>13</sup>
- More women who have strokes die from them compared with men. However, stroke is more common in men compared with women by the age of 75.<sup>14</sup>

<sup>9</sup> National Audit Office, 2005, *Reducing Brain Damage: Faster access to better stroke care*

<sup>10</sup> MORI poll, 2005; commissioned by the Stroke Association

<sup>11</sup> National Audit Office, 2005, *Reducing Brain Damage: Faster access to better stroke care*

<sup>12</sup> Ibid.

<sup>13</sup> Ibid.

<sup>14</sup> World Health Organization, 2004, *The atlas of heart disease and stroke*

- People who are overweight or obese, and who also suffer from hypertension, have a higher risk of ischaemic stroke.
- A recent national survey of individuals with stroke revealed that while 89 per cent are satisfied with the care they received, almost half are dissatisfied with the information they received and 52 per cent wished they had been more involved in their care. Carers, too, are often dissatisfied with the amount of information they are given.<sup>15</sup>

## Introduction

3. Lack of awareness of stroke is a significant problem. People do not know what a stroke is, what the symptoms are, or that it is a treatable disease that warrants the same response as a heart attack. Nor do they know what their own risk of having a stroke is, how to reduce that risk, or that stroke is largely preventable. Knowledge about stroke is also low among health and social care professionals.



## QM1. Awareness raising

### Marker of a quality service

- Members of the public and health and care staff are able to recognise and identify the main symptoms of stroke and know it needs to be treated as an emergency.

### Rationale

4. We know that a fast response to stroke reduces the risk of death and disability (see Chapter 2). However, this cannot be delivered without recognition of the symptoms of stroke and without responsive systems. To initiate an emergency response to a suspected stroke, it is crucial that staff who have contact with the public (including GP receptionists, NHS Direct call handlers, ambulance control call handlers, hospital triage staff, social care staff and allied health professionals) are able to recognise the symptoms of stroke or TIA, even when they cannot see the individual, and that they all share a common understanding of the importance of dealing with stroke as rapidly as possible.
5. Commissioners have a role to play in raising both public and professional awareness of stroke, and in doing so to ensure that people receive the right care. Part of building a good stroke service means including stroke awareness as part of staff training (see Chapter 4). Initially the focus may be on frontline staff. Many voluntary organisations already support this process at a local level, providing information, such as leaflets advising on stroke prevention, and support for those who have had a stroke and their carers.

<sup>15</sup> Healthcare Commission, 2006, *Survey of patients 2006, Caring for people after they have had a stroke: A follow-up survey of patients*

## Action needed

- Review local training plans for key frontline staff to ensure that training includes the use of the FAST test to recognise stroke symptoms (see Chapter 2 for importance of FAST response).
- Establish local initiatives to support the national programme (see Chapter 5).

## Measuring success

- Greater proportion of individuals who seek medical attention within two hours of stroke symptom onset
- Greater proportion of individuals with a suspected acute stroke seen within the recommended time window (currently three hours)
- Greater proportion of individuals with a suspected stroke receiving Category A, or at least Category B, response from ambulance crews<sup>16</sup>

## QM2. Managing risk

### Markers of a quality service

- Those at risk of stroke and those who have had a stroke are assessed for and given information about risk factors and lifestyle management issues (exercise, smoking, diet, weight and alcohol), and are advised and supported in possible strategies to modify their lifestyle and risk factors.
- Risk factors, including hypertension, obesity, high cholesterol, atrial fibrillation (irregular heartbeats) and diabetes, are managed according to clinical guidelines, and appropriate action is taken to reduce overall vascular risk.

### Rationale

6. Promoting healthy living is very important in helping to prevent stroke, particularly in disadvantaged areas and groups. Healthy lifestyles and management of specific risk factors reduce the risk of an initial stroke and the risk of a subsequent stroke. It is estimated that 20,000 strokes a year could be avoided through preventive work on high blood pressure, irregular heartbeats, smoking cessation, and wider statin use.<sup>17</sup> Preventing strokes can not only reduce the associated suffering, morbidity and mortality caused by strokes; it may also lead to NHS savings, as each stroke costs approximately £15,000 to treat over five years.<sup>18</sup>
7. For those who have already had a stroke or TIA, prevention advice is even more important. This means assessing individuals for their risk factors and giving them information about possible strategies to modify their lifestyle that can reduce their

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<sup>16</sup> Department of Health, 2006, *ASSET 2 – Action on Stroke Services: an Evaluation Toolkit for commissioners*, London, DH

<sup>17</sup> Ibid.

<sup>18</sup> National Audit Office, 2005, *Reducing Brain Damage: Faster access to better stroke care*

risk. GPs need to actively manage these conditions in line with national guidelines (see Annex B: 'Key resources').

8. We know that some groups (e.g. people from black and minority ethnic communities and the economically disadvantaged) are at greater risk, and for example South Asian people are less likely to have hypertension managed.<sup>19</sup> This means that targeting prevention work at those groups has the potential to lead to significant results. However, more innovative ways of working may be needed to ensure that the message is received by those who need it. That may mean taking services closer to the community and greater voluntary sector involvement in service planning and provision at all levels. Targeted prevention schemes can be very effective. For example, a Stroke Association health promotion scheme in Hull provides intensive follow-up and support to help individuals make necessary changes to their lifestyle, thus reducing the risk of stroke or recurrent stroke. The scheme has had a proven positive effect in terms of an increase in stroke prevention knowledge, and changes in attitude and behaviour.<sup>20</sup>
9. Primary care services are at the forefront of activity to encourage people to change their lifestyle in order to reduce the risk of ill-health, including stroke, as GPs manage risk factors according to national guidelines.<sup>21</sup> It is important that all primary care professionals (e.g. GPs, nurses and allied health professionals) update and maintain their knowledge of these guidelines and implement them in their practice, specifically targeting higher-risk groups. The Quality and Outcomes Framework (part of the GPs' contract) includes a number of quality indicators relating to measurement of risk associated with vascular disease, for example a section devoted to recording diagnosis and ongoing management of high blood pressure. This has already had a positive impact on management of hypertension in primary care. Social care services also work in partnership with primary care and the voluntary sector to deliver healthy living support, for example by using day services and other commissioned services.
10. *Commissioning framework for health and well-being* set out ways in which practice-based commissioners can use NHS money flexibly on non-health interventions to improve health and well-being outcomes.<sup>22</sup> This could include exercise classes, or weight management programmes. Further details about these flexibilities will be set out in the practice-based commissioning clarifying guidance, which will be published alongside the 2008/09 NHS operating framework.
11. Adult social care workers, along with staff in the voluntary sector, can be key providers of generic healthy living information, specific information on stroke, and delivery of services for those who have had a stroke and their carers. A partnership approach across

<sup>19</sup> Cappuccio FP, 1997, *Prevalence, detection, and management of cardiovascular risk factors in different ethnic groups in south London*

<sup>20</sup> Rennison C, Barker M and Marshall M, et al., 2002, *Stroke prevention in action project – Kingston upon Hull*, Sheffield, Sheffield University and the Stroke Association

<sup>21</sup> Royal College of Physicians, 2004, *National Clinical Guidelines for Stroke*, Second edition, prepared by the Intercollegiate Stroke Working Party, London, RCP

<sup>22</sup> Department of Health, 2006, *Commissioning Framework for Health and Well-being*, London, DH

services is likely to deliver the best results. For example, social services and the NHS are already working together to develop 'information prescriptions' providing a structure around information provision, and in the provision of equipment and minor adaptations.

12. ASSET 2 and *Improving Stroke Services: a guide for commissioners* can assist commissioners when they are assessing how best to organise multidisciplinary services. ASSET shows how many lives could be saved through improved prevention measures.<sup>23</sup>

## Action needed

- Commissioners and providers use ASSET to establish a baseline and to ensure that there are systems in place locally for the following key prevention measures:
  - managing hypertension so systolic blood pressure is below 140 mmHg;
  - warfarin for individuals with atrial fibrillation;
  - statin therapy for all people with more than 20 per cent risk of cardiovascular disease within ten years; and
  - smoking cessation for all individuals who have had a stroke or TIA.
- Review information and advice strategies to ensure that clear, consistent, culturally sensitive messages are being given to those who have had a stroke, their families and those at high risk.
- Ensure that stroke features in local needs assessment activities (see Chapter 5 in relation to Joint Strategic Needs Assessments).
- Directors of Public Health support the prevention message, particularly in disadvantaged areas and groups, and incorporate stroke into existing healthy lifestyle or information programmes. Where appropriate, links could be made to the forthcoming cross-government strategy for tackling obesity.
- As part of the Quality and Outcomes Framework, participating GPs produce a register of patients who have had a stroke or TIA, which forms the basis of a suite of indicators to provide quality of care. GPs should maintain the stroke register in line with the business rules and guidance that support the Quality and Outcomes Framework.

## Measuring success

- Greater proportion of individuals who have a history of stroke or cardiovascular disease, or who are at a high risk, who have had advice and/or are receiving treatment

## QM3. Information, advice and support

### Marker of a quality service

- People who have had a stroke, and their relatives and carers, have access to practical advice, emotional support, advocacy and information throughout the care pathway and lifelong.

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<sup>23</sup> Department of Health, 2006, *Improving Stroke Services: a guide for commissioners*, London, DH



## Rationale

13. Individuals who have had a stroke, and their relatives and carers, want to be kept informed, be included and have a clear, consistent point of contact throughout the care pathway, for as long as they live with the effects of stroke, which for many people will be life-long. Stroke can affect all aspects of life and may require considerable changes in daily activity. People who have experienced stroke and their carers benefit from consistent support in accessing information about their condition, and knowing how to access a full range of services from the NHS, social care and others. They also ask for more support in navigating the health and social care systems. This is important whether people are returning to their own home or going into a care home.
14. Service providers often work closely with voluntary sector organisations, which have traditionally undertaken this information and navigation role in some areas. This may take the form of a support worker, who can provide practical advice, information, signposting, advocacy and emotional support on a short- or long-term basis both to individuals who have had a stroke and to their carers. A national helpline and website with a variety of information and support are available to individuals and their carers from the Stroke Association.<sup>24</sup> Another example is the Brain and Spine Foundation Information Access Toolkit for professionals and individuals and their families to access information.<sup>25</sup>
15. The information needs of people who have had a stroke and their carers are diverse and change over time. Quality information and education, provided at the right time and in an accessible format, can improve opportunities for choice and levels of independence.<sup>26</sup> It can also enhance morale, confidence and well-being.
16. Good information needs to be tailored to individual requirements, sensitive to cultural needs, and flexible enough to meet the different requirements of different people. A significant proportion of people have aphasia as a result of stroke, which means they find it difficult to speak, read, write or understand what people are saying, especially if they are rushed or under pressure. It is important to provide information in a variety of ways, for example by supporting verbal information with written information or diagrammatic material. Good examples of accessible information include Connect's *Stroke Talk* and *The Stroke and Aphasia Handbook*.<sup>27</sup>
17. This is an important area for local authorities, health services and the voluntary sector to work on together, and they should consult people who have had a stroke and their carers on the relevance, suitability and completeness of materials to meet their individual needs.

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<sup>24</sup> Stroke Association helpline: 0845 3033 100 and website: [www.stroke.org.uk](http://www.stroke.org.uk)

<sup>25</sup> Available from: [www.brainandspine.org.uk/information/information\\_access\\_toolkit/index.html](http://www.brainandspine.org.uk/information/information_access_toolkit/index.html)

<sup>26</sup> Department of Health, 2004, *Better information, better choices, better health: Putting information at the centre of health*, London, DH

<sup>27</sup> Available from: [www.ukconnect.org/publications.aspx](http://www.ukconnect.org/publications.aspx)

## Action needed

- Commissioners ensure that people who have had a stroke, and their families and carers, are informed and empowered to take control of their care and support, by:
  - reviewing current information, advice and support;
  - involving voluntary sector organisations;
  - ensuring that service is in place to support people – providing information, advice and practical support;
  - including information to signpost people back into services if their needs change; and
  - ensuring that messages are consistent across health and social care services.

## Measuring success

- Systems in place to provide prompt, sensitive information in a variety of formats accessible to all those who have experienced a stroke, and their carers, with clear routes to accessing information life-long, where needed
- Survey to determine if advice and support matches individual needs

## Training for individuals and carers





## QM4. Involving individuals in developing services

### Marker of a quality service

- People who have had a stroke and their carers are meaningfully involved in the planning, development, delivery and monitoring of services. People are regularly informed about how their views have influenced services.

### Rationale

18. The Government's 2005 White Paper on health and social care, *Our health, our care, our say*, and the *Commissioning framework for health and well-being* emphasised the need for people's voices to be heard at a local level where spending decisions are taken, and it will be important to include those who have had a stroke in these discussions.
19. Involving people who have had a stroke and their carers in the development of services at the outset can help drive improvement and tackle problems.<sup>28</sup> For example, consulting people with stroke and their carers on the relevance, suitability and completeness of services and resources to meet their individual needs will improve the quality of information that services provide. Regular audits involving people with stroke and their carers, including people with communication and cognitive difficulties, should improve the effectiveness of information provision. Voluntary sector organisations can be effective in supporting this.
20. Some people may have specific support needs (e.g. those with aphasia, or hard-to-reach groups such as people who do not have English as their first language) which need to be met to enable them to be involved in service development. Commissioners should take into account the needs of all the community in their planning.
21. This includes conducting an Equality Impact Assessment identifying how the different needs of their communities will be met in implementing changes. Strategic health authorities have a role in performance managing primary care trusts on their production of the Equality Impact Assessment and can check whether services are developing in line with any actions identified.

### Action needed

- Establish a mechanism for regular consultation and involvement of those who have had a stroke and their carers.
- Ensure that this facilitates the involvement of all groups who are affected by stroke.

### Measuring success

- Regular opportunities for people who have experienced stroke and their carers to have an effective voice in the development, delivery, quality and further assessment of stroke services.

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<sup>28</sup> Coulter A and Ellins J, 2007, 'Effectiveness of strategies for informing, educating, and involving patients', *British Medical Journal* 335, 24–27

# Chapter 2

## Time is brain



### Aims

1. The NHS to assess people experiencing a transient ischaemic attack (TIA) or minor stroke rapidly in order to minimise the chances of a full stroke occurring.
2. The NHS to treat people with suspected stroke as a medical emergency in order to provide optimal treatment and maximise the chances of independent living after stroke.

### Key facts

- Around 150,000 people per year have a suspected TIA or minor stroke<sup>29</sup> but currently only 35 per cent are seen and investigated in a neurovascular clinic within seven days.<sup>30</sup>
- There is a 20 per cent risk of a full stroke within the first four weeks after a TIA.<sup>31</sup>
- Only 12 per cent of hospitals have protocols in place with ambulance services for the rapid referral of those with suspected stroke and less than 50 per cent of hospitals with acute stroke units have access to brain scanning within three hours of admission to hospital.<sup>32</sup>
- Less than 1 per cent of patients with ischaemic stroke received thrombolysis (treatment with clot-busting drugs) in 2006.
- Although two-thirds of stroke patients are managed on stroke units at some time during their hospital stay, only about 10 per cent of patients are likely to be admitted directly to an acute stroke unit.<sup>33</sup>

<sup>29</sup> Giles MF and Rothwell PM, 2007, 'Substantial underestimation of the need for outpatient services for TIA and minor stroke in the UK', *Cerebrovasc Dis* 23 (suppl. 2), 17

<sup>30</sup> Clinical Effectiveness and Evaluation Unit, Royal College of Physicians, 2007, *National Sentinel Stroke Audit 2006*

<sup>31</sup> Ibid.

<sup>32</sup> Clinical Effectiveness and Evaluation Unit, Royal College of Physicians, 2007, *National Sentinel Stroke Audit 2006*

<sup>33</sup> Ibid.

## Introduction

3. A more urgent response to both stroke and TIA will save lives and reduce long-term disability. Stroke is a treatable condition. Intensive physiological and neurological monitoring in the early phase of a stroke supports early treatment that halts stroke progression and prevents more brain cells being damaged. Investigating and treating high-risk patients with TIA within 24 hours could produce an 80 per cent reduction in the number of people who go on to have a full stroke.<sup>34</sup>

## TIA and minor stroke

### QM5. Assessment – referral to specialist

#### Markers of a quality service

- Immediate referral for appropriately urgent specialist assessment and investigation is considered in all patients presenting with a recent TIA or minor stroke
- A system which identifies as urgent those with early risk of potentially preventable full stroke – to be assessed within 24 hours in high-risk cases; all other cases are assessed within seven days
- Provision to enable brain imaging within 24 hours and carotid intervention, echocardiography and ECG within 48 hours where clinically indicated.

#### Rationale

4. Judging the likely early risk of a recurrent stroke will determine the response to a TIA or minor stroke. This will represent a challenging step change in the handling of TIA and minor stroke cases. The evidence for treating TIA has developed significantly in the past few years: the time in which there is a significant risk of having a major stroke is now acknowledged as much shorter, which means the response needs to be urgent. For those individuals attending primary care, advice needs to be given about taking aspirin and avoiding driving following a suspected TIA, in addition to rapid referral to emergency care.
5. All patients with minor stroke and all higher-risk patients with TIA and minor stroke (e.g. ABCD2 score  $\geq 4$  – see Glossary) need to be assessed by a specialist and treated within 24 hours. Patients assessed as an emergency in the community should be taken by ambulance to an appropriate acute stroke service if their symptoms have not resolved, or if they are otherwise considered to be at high risk of stroke. Patients who attend emergency departments, out-of-hours treatment centres or similar providers soon after a TIA or minor stroke must be treated and must not be sent home and simply told to see their GP in due course.

<sup>34</sup> Rothwell PM, et al., 2007, 'Effect of urgent treatment of transient ischaemic attack and minor stroke on early recurrent stroke (EXPRESS study): a prospective population-based sequential comparison', *Lancet* 370, 1432–42

6. An urgent assessment service provided by secondary care that allows same-day access for high-risk cases may best be achieved by allowing open-access for GPs, emergency department staff, paramedics and other providers. Appointment-based systems may introduce administrative delays.
7. Those at highest risk may justify immediate hospital admission. High-risk patients who are not felt to require immediate hospital admission have better outcomes if they are assessed, investigated and treated no later than 24 hours after referral (including cases presenting on weekends or public holidays). Treating TIA and minor stroke in this way will not only save lives, but can represent savings in the long term, because of fewer acute strokes and heart attacks. The ambition is for a twenty-four hour, seven day a week service to be available.
8. Lower risk patients with TIA or minor stroke are best investigated within seven days of the event.<sup>35</sup> Non-urgent referral for TIA or minor stroke is appropriate only for very low-risk patients, such as those presenting with events that occurred several weeks or months previously.

## Imaging

High-quality imaging of the brain and blood vessels is a key part of a successful stroke service. Currently, computed tomography (CT) scans are sufficient to determine whether a stroke is due to a clot or a bleed, but the higher spatial resolution of magnetic resonance imaging (MRI) is better for determining whether the diagnosis for TIA is correct and how large any infarction may be. Both MRI and CT imaging will continue to have a role in the immediate term, but it is inevitable that advances will be made and therefore imaging for both stroke and TIA needs to be kept under review. It is a rapidly changing field and any definitive answer will soon be out of date. The Department of Health (DH) will be developing a stroke and TIA imaging guide to assist local decision-makers and to give further opportunity for the options to be discussed.

9. About 80 per cent of TIAs and minor strokes require scanning of the arteries around the throat, which provide blood supply to the brain. 'Carotid imaging' (Doppler ultrasound, magnetic resonance angiogram (MRA) or a computed tomography angiogram (CTA))<sup>36</sup> should ideally be performed at initial assessment and should not be delayed for more than 24 hours after first clinical assessment in TIA or minor stroke patients at higher risk of stroke (e.g. ABCD2 score  $\geq 4$ ) or in patients with non-cardioembolic carotid-territory minor stroke. DH recognises that this is an ambitious vision and is in discussion with the relevant professional colleges and societies on ways to translate it into reality.

<sup>35</sup> Coull A, Lovett JK and Rothwell PM, on behalf of the Oxford Vascular Study, 2004, 'Early risk of stroke after a TIA or minor stroke in a population-based incidence study', *British Medical Journal* 328, 326–8

<sup>36</sup> MRA and CTA use contrastive dyes to enhance the image of blood vessels in the brain

10. MRI, including diffusion-weighted imaging (DWI), gradient echo imaging (GRE) and MRA, is the most useful imaging for TIA and minor stroke. Rapid (i.e. with 24 hours of referral) MRI needs to be performed in all patients seen acutely after a TIA or minor stroke in whom there is uncertainty about the diagnosis, vascular territory or underlying cause.
11. In those patients with a clinical need, echocardiography and 24-hour electrocardiogram (ECG) should be performed within 48 hours of initial assessment and the results acted upon immediately in cases where anticoagulation is required.
12. These markers are supported by quality requirements 2 and 3 of the *National Service Framework for Long-term Conditions*: 'early recognition, prompt diagnosis and treatment' and 'emergency and acute management'.

## Action needed

- Local referral protocols should be agreed between primary and secondary care to facilitate the timely assessment of people who have had a TIA or minor stroke.
- Review access to brain imaging.
- Estimate the likely impact on demand for brain imaging.

## Measuring success

- Greater proportion of people who have had a TIA or minor stroke who have received a specialist assessment and brain scan within 24/48 hours or seven days, according to risk
- Reduced average time to carotid imaging
- Lower proportion of patients having a major stroke prior to investigation
- Greater proportion of people started on aspirin immediately

## QM6. Treatment

### Marker of a quality service

- All patients with TIA or minor stroke are followed up one month after the event, either in primary or secondary care.

### Rationale

13. All patients with suspected TIA or minor stroke who are not already taking regular aspirin should be given 300mg aspirin immediately, or other agents as further evidence emerges.<sup>37</sup>
14. Carotid intervention for recently symptomatic severe carotid stenosis should be regarded as an emergency procedure in patients who are neurologically stable, and should ideally be performed within 48 hours of a TIA or minor stroke.

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<sup>37</sup> Rothwell PM, et al., 2007, 'Effect of urgent treatment of transient ischaemic attack and minor stroke on early recurrent stroke (EXPRESS study): A prospective population-based sequential comparison', *The Lancet* 370, 1432–42

15. Investing in services to diagnose TIA and minor stroke and manage subsequent risk of stroke will result in savings to acute care costs, as more strokes will be prevented.
16. People who have had a stroke or TIA also need information and advice, particularly on smoking cessation, diet, exercise, alcohol, driving and what to do in the event of a recurrent TIA or stroke. Action may also be needed to manage other risk factors such as diabetes, hypertension, hyperlipidaemia or ischaemic heart disease. Individuals can be encouraged to take responsibility for monitoring and treating their own vascular risk factors by provision of personalised risk factor profiles, individualised targets and record sheets for ongoing monitoring of risk factors.
17. A follow-up one month after the event, either in primary or secondary care, means that medication and other risk factor modification can be assessed, and screening for cognitive or other subtle neurological impairments should be performed. Any neurological deterioration or recurrence should trigger further investigation.
18. These markers are supported by quality requirements 2 and 3 of the *National Service Framework for Long-term Conditions*: 'early recognition, prompt diagnosis and treatment' and 'emergency and acute management'.

## Action needed

- Establish a clear pathway for managing TIA and minor stroke cases – high-risk and others.
- Establish a pathway for urgent carotid intervention.

## Measuring success

- Greater proportion of people who have had a TIA or minor stroke who have received treatment within 24/48 hours.
- Greater proportion of people who receive a carotid intervention within 24/48 hours, according to risk.
- Smaller proportion of people having a major stroke prior to treatment.

# Stroke

## QM7. Urgent response

### Marker of a quality service

- All patients with suspected acute stroke are immediately transferred by ambulance to a receiving hospital providing hyper-acute stroke services (where a stroke triage system, expert clinical assessment, timely imaging and the ability to deliver intravenous thrombolysis are available throughout the 24-hour period).



## Rationale

19. Typically, 1.9 million neurons are lost for each minute a stroke goes untreated. Every stage of the journey until treatment is received is therefore time critical.
20. The first steps to accessing emergency treatment is a rapid response to a 999 call for suspected acute stroke; rapid assessment utilising a pre-hospital assessment tool (e.g. FAST – see Glossary for explanation) by the ambulance crew and blue light transfer with pre-alert to a receiving hospital able to offer hyper-acute services with appropriate 24-hour expertise for all those who are likely to benefit from immediate treatment, including intravenous thrombolysis. Ambulance services are working with DH on proposals for improving the ability of ambulance medical dispatch systems to determine stroke calls that meet the FAST criteria and allow ambulance control staff to make a more appropriate response, which might be a category A response within eight minutes where indicated.
21. Thrombolysis for treatment of stroke must start within 3 hours of the onset of the stroke symptoms and after prior exclusion of intracranial haemorrhage by means of appropriate imaging techniques. The marketing authorisation states that thrombolytic treatment must be performed by a physician specialised in neurological care.<sup>38</sup>
22. For those people who call 999 when they first experience symptoms, thrombolysis can be an effective treatment where it can be delivered within three hours, and the patient should be triaged to a hospital which can deliver the drug. For those who delay before calling for professional help and so reduce the time available, it may be more appropriate to transfer to the nearest hospital with an acute stroke unit. This time window may change as the evidence base increases.
23. This marker is supported by quality requirements 2 and 3 of the *National Service Framework for Long-term Conditions*: 'early recognition, prompt diagnosis and treatment' and 'emergency and acute management'.

## Action needed

- Commissioners to ensure that protocols are in place for the rapid transfer of people with suspected acute stroke to a hyper-acute stroke unit. This will need discussion across a network of stroke service providers to agree which centre(s) will provide these services (and their catchment areas).
- Ambulance trusts and acute trusts to agree on the local pathway, which makes clear which patients meeting the FAST criteria are to be transferred for hyper-acute stroke care with a pre-alert to the receiving hospital, and which are to be taken to the nearest emergency department.

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<sup>38</sup> National Institute for Health and Clinical Excellence, 2007, *Alteplase for the Treatment of Acute Ischaemic Stroke*



- Ambulance trusts to ensure that crews are trained in stroke recognition (e.g. FAST) and treatment in accordance with Joint Royal College Ambulance Liaison Committee guidelines<sup>39</sup> and the Royal College of Physicians' pre-hospital guidelines.

## Measuring success

- Protocol in place between ambulance service and receiving hospitals for a rapid response for stroke patients
- Improved speed of response for stroke patients
- Regular reviews of operation of the locally agreed pathway to check that people suffering stroke are being appropriately transferred

### Using a network approach to manage the stroke care pathway

Stroke networks are beginning to develop but most are in the early stages.

It is becoming increasingly impractical for organisations to offer care pathways that are safe, of high clinical quality and responsive to patients without being part of well-defined networks. It is unlikely that services which are not part of a network will be adequate.

Stroke networks include all healthcare organisations involved in the provision of services, for example acute trusts, ambulance trusts and primary care trusts. Networks make the most effective use possible of resources and expertise.

The average district general hospital will not have consultants with a full range of expertise in all the sub-disciplines available around the clock, and it would be wasteful for all hospitals to invest in high-tech facilities which were only used for a small number of people. Provision of hyper-acute stroke services is one area where networks serving a population of between 500,000 and two million can help to shape the most appropriate pattern of service for local needs (see Chapter 4, 'Working together').

## QM8. Assessment

### Markers of a quality service

- Patients with suspected acute stroke receive an immediate structured clinical assessment from the right people.
- Patients requiring urgent brain imaging are scanned in the next scan slot within usual working hours, and within 60 minutes of request out-of-hours with skilled radiological and clinical interpretation being available 24 hours a day.

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<sup>39</sup> Available from: [www.jrcalc.org.uk](http://www.jrcalc.org.uk)

- Patients diagnosed with stroke receive early multidisciplinary assessment – to include swallow screening (within 24 hours) and identification of cognitive and perceptive problems.

## Rationale

24. The initial structured assessment, for example the recognition of stroke in the emergency room (ROSIER)<sup>40</sup> scale, in a high-dependency area such as the emergency department or medical assessment unit, is needed to determine the diagnosis and whether urgent brain imaging is required. There are several conditions with symptoms that mimic stroke (e.g. syncope and seizures), and these need to be excluded first.
25. The urgent brain scan is needed to differentiate between those who have had an ischaemic stroke and those who have had a stroke due to primary intracerebral haemorrhage as it is not possible to do this by clinical examination alone. Thrombolysis given to a person with a haemorrhage would have fatal results.
26. A quick decision is needed within a short time window to determine whether or not the patient has had a haemorrhage. Currently, CT scanning is adequate for this and will allow decisions about thrombolysis to be made for most patients (see 'Imaging' box on page 24). It is suggested that these patients be scanned in the next scan slot within usual working hours, and within 60 minutes of a request out-of-hours. This mirrors the recently updated NICE guidelines on head injury.<sup>41</sup>
27. Not everyone will be eligible to receive thrombolysis, but they can still benefit from faster entry into acute stroke specialist services. Some patients with stroke may have other medical conditions that will influence decisions about their care. Local protocols need to take this into account.
28. Once diagnosed with a stroke, patients need to be screened for swallowing before eating or drinking and at least within the first 24 hours.
29. Protocols may need to be developed to ensure that the same access to stroke specialists is available to those who have a stroke while they are in hospital.
30. These markers are supported by quality requirements 2 and 3 of the *National Service Framework for Long-term Conditions*: 'early recognition, prompt diagnosis and treatment' and 'emergency and acute management'.

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<sup>40</sup> Nor AM, Davis J, Sen B, et al., 2005, 'The Recognition of Stroke in the Emergency Room (ROSIER) scale: development and validation of a stroke recognition instrument', *Lancet Neurology* 4(11), 727–34

<sup>41</sup> National Collaborating Centre for Acute Care, 2007, *Triage, assessment, investigation and early management of head injury in infants, children and adults*, commissioned by the National Institute for Health and Clinical Excellence

## Action needed

- Train emergency department and medical assessment unit staff in structured clinical assessments for stroke (e.g. ROSIER).
- Review of access to brain imaging and plan to enable slots at the appropriate time.
- Ensure timely multidisciplinary assessment once stroke is diagnosed.

## Measuring success

- Greater proportion of patients scanned within one hour
- Greater proportion of patients scanned within 24 hours
- Greater proportion of patients screened for swallow disorders within 24 hours

## QM9. Treatment

### Markers of a quality service

- All stroke patients have prompt access to an acute stroke unit and spend the majority of their time at hospital in a stroke unit with high-quality stroke specialist care.
- Hyper-acute stroke services provide, as a minimum, 24-hour access to brain imaging, expert interpretation and the opinion of a consultant stroke specialist, and thrombolysis is given to those who can benefit.
- Specialist neuro-intensivist care including interventional neuroradiology/neurosurgery expertise is rapidly available.
- Specialist nursing is available for monitoring of patients.
- Appropriately qualified clinicians are available to address respiratory, swallowing, dietary and communication issues.

## Rationale

### Stroke units

31. If timely access to stroke units was increased to 75 per cent of stroke patients, this would prevent over 500 deaths per year and result in over 200 more independent individuals.<sup>42</sup> An acute stroke unit is one that will be providing high-dependency care including physiological, neurological monitoring and rapid treatment of stroke and associated complications, early rehabilitation and palliative care.
32. There is overwhelming evidence that stroke units reduce death and increase the number of independent and non-institutionalised individuals.<sup>43,44</sup> The benefits have been proven

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<sup>42</sup> Clinical Effectiveness and Evaluation Unit, Royal College of Physicians, 2007, *National Sentinel Stroke Audit 2006*

<sup>43</sup> Stroke Unit Trialists' Collaboration, 1997, 'Collaborative systematic review of the randomised trials of organised inpatient (stroke unit) care after stroke', *British Medical Journal* 314, 1151–9

<sup>44</sup> Stroke Unit Trialists' Collaboration, 2001, 'Organised inpatient (stroke unit) care for stroke', *Cochrane Database of Systematic Reviews*, Issue 3

for five and ten years.<sup>45</sup> Survival is strongly associated with processes of care that are carried out significantly more frequently on stroke units, such as early mobilisation, early feeding and measures to prevent aspiration. Speech and language therapists, physiotherapists, occupational therapists and dietitians have specific contributions to make in delivering these particular aspects of care. The probable explanation for higher survival and lower institutionalisation rates are the significant differences in both multidisciplinary team working – such as early assessment, goal setting and discharge planning – and in medical management.

33. The majority of stroke patients will require high-dependency care on an acute stroke unit for the first 24 hours of the illness. Most stroke progression occurs within the first 24 hours and so prompt access to an acute stroke unit is needed. Effective early management of stroke will reduce the need for intensive care beds. However, a small proportion of patients will require intensive care during the duration of their hospital admission.
34. Most hospitals now have a stroke unit, and the challenge is both to bring all units up to the standard of the best and to develop some of these to provide hyper-acute services. The Intercollegiate Stroke Working Party publishes guidelines on good acute stroke care.<sup>46</sup> Ensuring minimal competencies of staff in non-specialist areas in dealing with people with stroke is addressed in Chapter 4.

### **Acute stroke units need a multidisciplinary team, with the skills and equipment for:**

- appropriate care and monitoring (e.g. neurological function, blood pressure, cardiac rhythm, respiratory function, oxygen saturation and blood glucose);
- access to physiotherapy (including respiratory physiotherapy);
- access to speech and language therapy (including swallowing);
- access to dietetic services (including nutrition screening);
- providing critical care for stroke patients who require enhanced monitoring or who develop complications;
- prompt access to support from specialist critical care colleagues;
- good communications with patients, their families and the patient's GP.

### **Thrombolysis**

35. If 10 per cent of acute stroke patients were to receive thrombolysis, over 1,000 people per year would regain independence rather than die or be dependent in the long term.<sup>47</sup>

<sup>45</sup> Indredavik B, Bakke F and Slørdahl SA, et al., 'Stroke Unit Treatment: 10-Year Follow-Up', *Stroke*, 1999, 30, 1524–7

<sup>46</sup> Royal College of Physicians, 2004, *National Clinical Guidelines for Stroke*, Second edition, prepared by the Intercollegiate Stroke Working Party, London, RCP

<sup>47</sup> Department of Health, 2006, *ASSET 2 – Action on Stroke Services: an Evaluation Toolkit for commissioners*, London, DH

36. There are currently insufficient specialist stroke services to be able to provide the level of care identified above for delivering thrombolysis. Thrombolysis should only be introduced when the specialist medical and nursing care is always available. This can be addressed by the development of hyper-acute centres in a 'hub and spoke model' supported by an increase in the range of clinicians able to provide specialist acute input, for example acute physicians and specialist nurses. These themes are explored in more detail in Chapter 4, 'Working together'.

### **A thrombolysis service requires:**

- rapid response and 'blue light' transfer by the ambulance service;
- a receiving hospital with 24-hour access to a stroke specialist, urgent brain scanning and expertise in interpretation; and
- direct admission to an acute stroke unit and sufficient specialist medical, nursing and allied health professional staff to provide 24-hour support.

### **Neuroscience expertise**

37. Facilities should also be available to investigate and treat unusual causes of stroke. There are relatively few indications for neurosurgery in patients with stroke, but appropriate intervention in specific cases such as cerebellar haematoma, hydrocephalus and massive peri-infarct oedema may be life-saving. The care of these patients is increasingly managed by a multidisciplinary team in a neurosciences centre consisting of a stroke specialist, neurosurgeon and interventional neuroradiologist. There may be a role for interventional neuroradiology (intra-arterial thrombolysis or angioplasty) in the management of basilar thrombosis. This team should have the responsibility for producing and monitoring local protocols for the referral and treatment of appropriate patients. A network approach may be required to develop an agreed protocol, so that each stroke unit is linked to a regional neurosciences centre for emergency review of local brain imaging – for example by electronic link and emergency transfer (and then repatriation) of appropriate patients. It is likely that delivering specialist neuro-intensivist care will only be possible through collaborative working and use of specialised services commissioning arrangements.
38. These markers are supported by quality requirements 2 and 3 of the *National Service Framework for Long-term Conditions*: 'early recognition, prompt diagnosis and treatment' and 'emergency and acute management'.

### **Action needed**

- Commissioners to contract for admission of all stroke patients to a stroke unit (meeting appropriate clinical standards) on the day of referral to hospital and for the majority of their stay.

- Commissioners and providers to review local needs and reconfigure beds and staffing to match capacity to demand, with the relative distribution of beds between acute, rehabilitation or combined stroke units dependent on local circumstances.
- Commissioners to work collaboratively using a network approach to ensure 24/7 coverage of acute stroke care capable of delivering thrombolysis.
- Commissioners to use Payment by Results tariffs to support thrombolysis provision.
- Strategic health authorities, through specialised commissioning arrangements, to support the co-ordination of the availability of specialist neuro-intensivist care, including interventional neuroradiology and neurosurgery expertise (see also Chapter 4 on stroke networks), including an estimation of the likely number of patients who will be referred.

## Measuring success

- Greater proportion of patients admitted to an acute stroke unit on day of admission
- Greater proportion of patients spending all their in-hospital time in a stroke unit
- Greater proportion of patients receiving thrombolysis
- Arrangements in place for referral treatment of unusual causes of stroke



# Chapter 3

## Life after stroke



### Aim

1. For those who have had a stroke and their relatives and carers, whether at home or in care homes, to achieve a good quality of life and maximise independence, well-being and choices.

### Key facts

- At present only around half of individuals who have experienced a stroke receive the rehabilitation to meet their needs in the first six months following discharge from hospital, falling to around a fifth in the following six months.<sup>48</sup>
- Three-quarters of younger individuals want to return to work.<sup>49</sup>
- A third of individuals develop depression.<sup>50</sup>
- A third of individuals experience communication difficulties.<sup>51</sup>
- Currently around a third of people who have strokes will die as a result; many of these people will not do so immediately, but within three months of the stroke.<sup>52</sup>

### Introduction

2. Ensuring the correct type and levels of support for people who have experienced stroke and for their family and carers is a key area of challenge for commissioners and providers. The aim is to achieve a good quality of life for individuals, their carers and relatives, and to support independent living. The support needs of people who have experienced stroke share some common features with those living with long-term

<sup>48</sup> Department of Health, 2005, *The National Service Framework for Long-term Conditions*, London, DH

<sup>49</sup> The Stroke Association and Different Strokes, 2006, *Getting back to work after stroke*

<sup>50</sup> Hackett ML, Yapa C, Parag V and Anderson CS, 2005, 'Frequency of depression after stroke: a systematic review of observational studies', *Stroke* 36 (6), 1330–40

<sup>51</sup> Enderby P and Phillipp R, 1986, 'Speech and Language Handicap: Towards knowing the size of the problem', *British Journal of Disorders of Communication* 21 (2), 151–65

<sup>52</sup> National Audit Office, 2005, *Reducing Brain Damage: Faster access to better stroke care*, London, NAO



conditions, and quality requirements from the long-term conditions National Service Framework (NSF) and the older people's NSF are of considerable relevance.<sup>53</sup>

**3.** The seven outcomes set out in *Our health, our care, our say* are relevant to people living with stroke:

- improved health and emotional well-being
- improved quality of life
- making a positive contribution
- choice and control
- freedom from discrimination
- economic well-being
- personal dignity.<sup>54</sup>

Commissioners should commission stroke services with these outcomes in mind.

- 4.** People who have had a stroke and their carers value continuity, being kept informed, being included and having a clear, consistent point of contact with services. Well-co-ordinated, partnership working between health and social care services is of central importance, but it needs to be flexible enough to bring in other services, such as employment, transport, housing and leisure services, where appropriate.
- 5.** Individuals affected by stroke and their relatives need to receive good-quality, appropriate, tailored and flexible rehabilitation: this will affect long-term recovery and reduce long-term disability. Stroke is a condition that can improve over many years, so people need both a focus on rehabilitation, to help them improve and recover, and support, to help them manage the disabling factors caused by a stroke that may continue in the long term.
- 6.** Commissioners will want to consider engaging a wide range of provision, including provision from the third sector, to meet the needs of the local population. Services should also be appropriate for all ages; one quarter of people who have a stroke are under 65 and may have particular needs.
- 7.** There are services provided by the voluntary sector that can provide a package for comprehensive support services for people affected by stroke. These include: family and carer support intervening soon after the event and providing information, advocacy and support; day care; services for people of working age; primary and secondary prevention; dysphasia and aphasia support groups; activity and rehabilitation programmes; and stroke clubs. These services are supported by volunteers and provide opportunities for individuals recovering from stroke to contribute their experience and encouragement to those at an earlier stage of the stroke journey.

<sup>53</sup> Department of Health, 2005, *The National Service Framework for Long-term Conditions*, London, DH; Department of Health, 2001, *The National Service Framework for Older People*, London, DH

<sup>54</sup> Department of Health, 2006, *Our health, our care, our say*, London, DH

## QM10. High-quality specialist rehabilitation

### Marker of a quality service

- People who have had strokes access high-quality rehabilitation and, with their carer, receive support from stroke-skilled services as soon as possible after they have a stroke, available in hospital, immediately after transfer from hospital and for as long as they need it.

### Rationale

8. Rehabilitation after stroke works. Specialist co-ordinated rehabilitation, started early after stroke and provided with sufficient intensity, reduces mortality and long-term disability. Early rehabilitation is effective when provided in specialist stroke units, or as part of properly organised early supported discharge and longer-term support in the community, according to need.<sup>55</sup>

#### Components of multi-faceted stroke specialist rehabilitation and support:

- mobility and movement;
- communication;
- everyday care activities e.g. dressing, washing, meal preparation;
- depression and distress;
- swallowing;
- nutrition;
- cognitive difficulties;
- vision and visual perceptual difficulties;
- continence; and
- relationships and sex.

9. As set out in the *National Service Framework for Older People*, rehabilitation on a stroke unit should be supported by a stroke-skilled multidisciplinary team, which includes a range of allied health professionals, and has strong links to social care. This would ensure that staff on rehabilitation units have the appropriate competencies to deal with the complex issues that patients present, including promotion of continence, maintenance of nutrition and skin health and management of communication impairments such as aphasia. The Cochrane review of stroke unit trials showed that not only did stroke rehabilitation units benefit all patients irrespective of age and severity, but that those with more severe stroke gained most.<sup>56</sup> Other settings, such as generic intermediate care beds, may not be as effective at improving outcomes

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<sup>55</sup> Langhorne P, et al., 2005, 'Early supported discharge services for stroke patients: a meta-analysis of individual patients' data', *Lancet* 365, 501–6

<sup>56</sup> Stroke Unit Trialists' Collaboration, 2001, *Organised inpatient (stroke unit) care for stroke*

for individuals, but may be appropriate in some settings, for example in more rural areas where people may benefit from being closer to home. Ensuring the knowledge, skills and experience of such specialist staff is addressed in Chapter 4.

10. Ideally the care environment will be designed or adapted for people who have had a stroke. They may benefit from being evaluated in an independent living unit under close supervision of the stroke unit staff. Failure to provide appropriate equipment can not only delay recovery but also limit the final level of independence. Stroke care in hospital requires an environment that is appropriate including:

- adequate hoisting facilities for those with a physical disability;
- adapted toilet and washing facilities;
- height-adjustable beds;
- sufficient single rooms for palliative care, infection control and those needing to be assessed for independent living;
- sufficient space and equipment for rehabilitation on the ward;
- easy access to aids for rehabilitation, such as manual and electric wheelchairs, adapted cutlery, chairs of the correct height and providing appropriate postural support, pressure-relieving equipment, aids to continence etc.;
- communal areas;
- private areas for individuals, family and carers;
- easy access to information – written, audio, web-based; and
- an upbeat and attractive environment to promote psychological well-being and a positive approach to recovery.

There may be specific groups of patients with exceptional needs to be accommodated, for example parents of young children and younger patients.

11. Where care is transferred from a stroke unit to in-patient intermediate care, better outcomes can be achieved when professionals with stroke expertise are part of the rehabilitation team and specialist input remains to oversee management and transfer back to the specialist unit if the individual is failing to thrive. In-patient intermediate care is unlikely to be appropriate for people with complex, unstable conditions.
12. Early supported discharge (ESD) to a comprehensive stroke specialist and multidisciplinary team (which includes social care) in the community, but with a similar level of intensity to stroke unit care, can reduce long-term mortality and institutionalisation rates for up to 50 per cent of patients and lower overall costs.<sup>57</sup> The focus should be on those patients who will most benefit: premature discharge to inadequate community facilities is likely to increase individuals' long-term dependency and therefore reduce the immediate savings achieved through a shorter length of stay.

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<sup>57</sup> Department of Health, 2005, *The National Service Framework for Long-term Conditions*, London, DH

13. Recovery can continue for many years after an individual has had a stroke, so it is important that commissioners consider how to provide access to services over the long-term.<sup>58</sup> Access to specialist rehabilitation is as important for those who do not go into intermediate care, and may need to follow on from ESD. The impact of a stroke may continue for as long as the person who has had a stroke lives, which means that services may need to be available for the whole of their life. Flexible, multidisciplinary services in the community can help people build on the improvements that they have made whilst in hospital or during ESD in a setting where they feel more comfortable and relaxed, while rebuilding their confidence and independence. There is evidence that co-ordinated community stroke teams prevent people from deteriorating once they return home. Some people may move into care homes, but can still benefit from rehabilitation, depending on individual needs.
14. Specialist teams may be more important in the early stages of rehabilitation, while generic teams can be appropriate for the later stages. However, the configuration of community teams is less important than ensuring that these teams are multidisciplinary and all staff have the right specialist skills to help rehabilitate people who have had a stroke. The skills of allied health professionals such as physiotherapists, occupational therapists and speech and language therapists are important, as are other services such as podiatry, continence services and community mental health services. Ensuring minimal competencies of staff in non-specialist areas for dealing with people with stroke is addressed in Chapter 4.
15. Targeted interventions can help specific problems such as communication, dressing, leisure and transport. Rehabilitation – support to regain well-being – requires rehabilitation specialists and continuing support from a wide range of community-based services, such as exercise classes, communication support groups, accessible further education and employment opportunities, arts and leisure activities, self-management activities and self-help groups, offered by appropriately trained and supported statutory and voluntary agencies. In this context, support provided by the stroke specialist voluntary sector becomes increasingly important. Services provided by voluntary organisations such as stroke clubs and communication support groups enable individuals who have had a stroke to engage with lay stroke specialists and others who have experienced a stroke.
16. As with acute care, rehabilitation develops as new technologies and therapies come on stream (for example Functional Electrical Stimulation, walking with a Space-trainer and constraint therapy for arm movement), and those who provide services will want to keep pace with developments.
17. Many people living with long-term disabilities have, in recent years, developed methods of participating in managing their own conditions, or in peer-support activities.

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<sup>58</sup> van der Gaag A, Smith L, Mowles C, Davis S, Moss B and Laing S, 2004, 'Therapy and support services for people with stroke and aphasia and their relatives; a six month follow up study', *Clinical Rehabilitation* 19 (4) 372–80

The Expert Patient Programme provides training for people in developing the skills they need to take effective control of their lives. There is scope to expand the range of 'self-management' activities available for people with stroke. Careful planning of the support systems required to enable people with stroke to participate in managing their own care is needed, especially to enable the inclusion of people with communication and cognitive difficulties. An Expert Carers Programme is also being developed and is expected to begin during 2008.

- 18.** This marker is supported by quality requirements 4 and 5 of the *National Service Framework for Long-term Conditions*: 'early and specialist rehabilitation' and 'community rehabilitation and support'.

## Action needed

- Ensure stroke units meet RCP guidelines.
- Consider how to meet the needs of the local population, and especially the needs of different black and ethnic minority communities.
- Commission services in partnership between health and social care services to ensure integrated care to support individuals.
- Commissioners should contract for ESD teams of stroke patients using ASSET to help determine the correct levels.
- Implement Payment by Results guidance on unbundling the national tariff for acute stroke to direct funding into specialist rehabilitation (whether to a rehabilitation unit, ESD or community team, or elsewhere).
- Develop ongoing rehabilitation in the community, provided by stroke-skilled people.
- Commission services to support self-care, e.g. Expert Patient Programmes, from a range of providers including the voluntary sector.
- Develop and support a wide range of local community-based and peer-delivered activities for people who have had strokes and their carers, involving the local voluntary sector, for example peer-led conversation groups and peer-support or befriending schemes.

## Measuring success

- Reduced readmission rates
- Reduced long-term dependency rates

## QM11. End-of-life care

### Marker of a quality service

- People who are not likely to recover from their stroke receive care at the end of their lives which takes account of their needs and choices, and is delivered by a workforce with appropriate skills and experience in all care settings.

## Rationale

19. Of the more than 45,000 people with stroke who die each year, many will do so with impaired communication and/or cognitive skills. Providing high-quality end-of-life care in such circumstances can be challenging and requires an appropriately skilled and experienced workforce. Judging when it might be more appropriate for someone who has had a stroke to receive end-of-life care rather than active rehabilitation and providing such care when communication is difficult is a considerable challenge and requires skilled decision-making and interaction from an experienced workforce. The needs and wishes of both the individual and their carer or family, if appropriate, should be sought as part of this process and should be reviewed regularly to ensure that their needs continue to be met throughout the last phase of life and into bereavement. This includes the management of pain and other symptoms, and the provision of psychological, social, spiritual and practical support. People in need of this care will often already be in hospital, but they may also be at home, in care homes or other care settings.
20. End-of-life care will need to be provided in line with best practice guidance. A number of approaches to support end-of-life care are currently being expanded across the country. These include:
  - Preferred Priorities for Care (PPC), which is an example of advance care planning. This is a patient-held document designed to support patient choice, ensuring that the information is shared with all health and social care staff involved in their care. Recording people's preferences for care helps to direct the planning and continuity of care.
  - The Gold Standards Framework (GSF), used mainly in the primary care setting, enables GPs to identify people approaching the end of their lives, assess their needs and plan appropriate care.
  - The Liverpool Care Pathway (LCP) for the dying is used to care for people in the last days or hours of life. It enables clinical staff to deliver high-quality care as death approaches, providing guidance on comfort measures, anticipatory prescribing, psychological and spiritual care and family support. It is mainly used in hospitals and hospices but is increasingly being adopted for use in other care settings.
21. In addition, the Department of Health (DH) is developing a new strategy for end-of-life care, which will deliver increased choice to all adults, regardless of their condition, about where they live and die.
22. This marker is supported by quality requirement 9 of the *National Service Framework for Long-term Conditions*: 'palliative care'.

## Action needed

- Review current provision and identify any gaps, including training needs of staff.
- Include appropriate management for end-of-life care in contracts.



## Measuring success

- Greater proportion of people who die in a place of their choice
- Positive responses to questionnaires from bereaved relatives and carers

## QM12. Seamless transfer of care

### Marker of a quality service

- A workable, clear discharge plan that has fully involved the individual (and their family where appropriate) and responded to the individual's particular circumstances and aspirations is developed by health and social care services, together with other services such as transport and housing.

### Rationale

23. Where health and social care services work together to facilitate a smooth return home it can help people recover quickly, reduce the pressure on the individual and their family and prevent unnecessary readmissions to hospital or care homes. Involving social workers in the multidisciplinary team at an early stage is an effective way to achieve this. The challenge is to ensure that individuals feel reassured that when they leave hospital they know what arrangements for ongoing care, support and rehabilitation have been made and how to access information and advice, as well as who will take forward the next stage of their rehabilitation and support. This may mean emergency packages of care are put in place while a full assessment is completed, and information is made accessible for people with communication and cognitive difficulties.
24. GPs already keep registers of all their patients who have had a stroke. A system that alerts them when someone leaves hospital will enable primary care to be part of the plan of support.
25. Providing the right home environment can be the key to helping people to get home, as small adaptations or equipment provided quickly mean that the individual is able to return home safely, and can prevent delayed discharges. Assessment for both short- and long-term needs should commence as early as possible in order that the appropriate equipment and/or adaptations are provided in a timely way to support rehabilitation. Occupational therapists play an important role and there may be a need for joint working protocols and integrated services to be put in place for assessment and delivery of these services. Although some equipment may already have been obtained to facilitate the transfer home, this may need to be reassessed to check for long-term needs.
26. This marker is supported by quality requirement 1 of the *National Service Framework for Long-term Conditions*: 'a person-centred service'.

## Action needed

- Commissioners of stroke care to set service level agreements with providers covering the quality and timeliness of information transfer and maximum waiting times for provision of community services, including the relevant quality markers for stroke from the quality schedule of contracts.
- Ensure strong relationship between stroke unit and community (including social care) teams.
- Care planning process built around the individual to consider a range of needs to support someone going home or to a care home (including their physical, communicative, cognitive, psychological and financial circumstances).
- Develop system to ensure that individuals receive copies of their own transfer of care summaries and are involved in planning their transfer of care.
- Ensure that those admitted to hospital only for a short period, with non-disabling stroke, also have appropriate arrangements made for their transfer of care.
- Ensure that there is an effective process to alert GPs when someone returns home.
- Engagement of voluntary sector agencies to provide information, support, advocacy and peer support.

## Measuring success

- Reduced readmission rates
- Reduced waiting times for provision of community therapy
- Positive responses from user satisfaction surveys

## QM13. Long-term care and support

### Marker of a quality service

- A range of services are in place and easily accessible to support the individual long-term needs of individuals and their carers.

### Rationale

27. The impact of stroke varies hugely, and so support in the long-term needs to be tailored to meet the individual's needs. A co-ordinated approach is needed, not just between health and social care, but also involving housing, transport, employment, education and leisure services, as well as the voluntary sector.
28. *Our health, our care, our say* identifies direct payments as key to personalised services.<sup>59</sup> For those assessed as being eligible for social care support from the local council, the option of direct payments will be available. Direct payments allow individuals to take control of the budget spent on their care, allowing them to buy the care that best suits their needs.

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<sup>59</sup> Department of Health, 2006, *Our health, our care, our say*, London, DH

29. People who have had a stroke can find that the accommodation they are in is no longer suitable. There are a range of solutions to this: for example, simple pieces of equipment can make a real difference. Increasingly, telecare and telehealth solutions can help people to live in their own homes for longer. The Disabled Facilities Grant can be used to help fund the provision of adaptations to enable disabled people to live as comfortably and independently as possible in their own homes. A wide range of work is eligible, including providing access to basic facilities within a home and facilitating access to and within the property. Nevertheless, in some cases people will require support to move to a new home.
30. The Supporting People Programme funds local authorities to provide services which help vulnerable and older people, including those with disabilities because of a stroke, to live independently. In the case of people who have had a stroke, Supporting People funding can be used to contribute towards costs, such as the employment of a home improvement agency to oversee all aspects of having a home adapted; or it can fund services which give a person who has experienced a stroke the confidence to continue to live independently and reduce the likelihood of them moving into residential care.
31. Many people experience emotional difficulties after a stroke, and this can have an impact on their long-term physical recovery and lead to depression and isolation.<sup>60</sup> Carers are also vulnerable to difficulties in coping and to depression.<sup>61</sup> This may make returning to activities and roles that were part of normal life before the stroke difficult.
32. People who struggle to adjust to the longer-term effects (both those who have had a stroke and their carers) need access to emotional support services. In the first instance, all staff working with stroke can, and often do, provide emotional and psychological support. These can range from access to good peer support or local counselling services through to referral for psychiatric and psychological services. Ideally, services need to develop long-term psychological and emotional support, with co-ordinated programmes starting with psychological support in hospital and longer-term support involving the voluntary sector. Services to support adjustment to long-term effects should also be provided to people with stroke who live in care homes.
33. Screening will identify those who can benefit from access to a broad range of mental health and psychological services. A number of allied health professionals can support access and may also be able to deliver psychological therapies – for example art therapists, music therapists and drama therapists use non-verbal approaches. Both nursing staff and allied health professionals can and do offer psychological support themselves. Services should consider how they will support access for people with communication and cognitive difficulties to these opportunities.

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<sup>60</sup> Robinson RG, 2006, 'Cognitive, behavioural and emotional disorders following vascular brain injury', *The Clinical Neuropsychiatry of Stroke* (second edition), New York, Cambridge University Press

<sup>61</sup> Grant JS, Glandon GL, Elliot TR, Giger JN and Weaver M, 2004, 'Caregiver problems and feelings experienced by family caregivers of stroke survivors the first month after discharge', *International Journal of Rehabilitation Research* 27, 105–11

34. Carers are vital in providing support for people who have had a stroke and medical professionals and providers must acknowledge this when looking at the long-term support for people who have had a stroke. Carers are entitled to an assessment in their own right for support, and access to ongoing, long-term support services such as planned short breaks and laundry and continence support services can enable carers to sustain care at home over the long term. The Carers Grant is given to councils to support the provision of these services for carers. The revision of the 1999 Prime Minister's Strategy on Carers is due to be published in Spring 2008. One of the key issues being raised in strategy consultation is recognition of carers as individuals in their own right.
35. Practice-based commissioners can use NHS money flexibly to purchase care, allowing carers to take a break, as set out in the *Commissioning Framework for Health and Well-being*.<sup>62</sup>
36. Younger people with stroke may have different needs. For example, they may have a family to support. Specific attention should be paid to the communication difficulties experienced by many individuals and the need to commission long-term support services from voluntary organisations that are able to meet these long-term needs.
37. This marker is supported by quality requirements 5, 7, 8 and 9 of the *National Service Framework for Long-term Conditions*: 'community rehabilitation and support,' 'providing equipment and accommodation,' 'providing personal care and support' and 'palliative care,' respectively.

## Action needed

- Review the long-term support available and whether it matches the needs of the local population for the long term.
- Use local voluntary sector stroke organisations to support people to consider having a direct payment (and in the future an individual budget).
- Consider how changing housing support needs are met, for example, by using Supporting People or the Disabled Facilities Grants (DFGs).
- Ensure a spectrum of provision for psychological and emotional support, including the voluntary sector.

## Measuring success

- Greater proportion of individuals affected by stroke to live independently
- Greater proportion of individuals with a direct payment/individual budget
- Greater proportion of individuals/carers who are screened to identify need for psychological support and whose identified needs are met
- Greater proportion of individuals/carers who receive an assessment
- Positive responses from user satisfaction surveys

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<sup>62</sup> Department of Health, 2006, *Commissioning Framework for Health and Well-being*, London, DH

## QM14. Assessment and review

### Markers of a quality service

- People who have had strokes and their carers, either living at home or in care homes, are offered a review from primary care services of their health and social care status and secondary prevention needs, typically within six weeks of discharge home or to care home and again before six months after leaving hospital.
- This is followed by an annual health and social care check, which facilitates a clear pathway back to further specialist review, advice, information, support and rehabilitation where required.

### Rationale

38. Following *Our health, our care, our say*, everyone with a long-term condition should be offered a care plan by 2010, and all primary care trusts and local authorities will need to have established joint health- and social care-managed networks and/or teams to support those with long-term conditions. Given the numbers of people with stroke who have long-term needs, commissioners would be advised to look at stroke as a key area in delivering this commitment.
39. A good assessment process for someone who has just had a stroke will involve a multidisciplinary person-centred assessment of the individual's needs and signposting to other services, such as housing or transport, for example, using the Single Assessment Process. Family members or friends who may be taking on a caring role are entitled to an assessment of their needs in their own right. Direct payments (or individual budgets in the future) should be considered for both individuals and carers.
40. It will be important to bear in mind that those who have had a stroke may have additional communication or cognitive support needs to be able to participate in the assessment. People for whom English is not their first language and those with literacy difficulties may also have different requirements and services need to be flexible enough to meet their needs.
41. In addition, those affected want to know how to seek further support when they need it. Tools for self-assessment are being developed to provide individuals with the ability to self-refer, either back into traditional services or to other places that can meet their needs. Commissioners may want to consider commissioning self-referral to services for service users and carers. The offer of regular review – after six weeks, six months and then annually – is one way to ensure people continue to feel supported. Of key importance is the enabling and supporting of people in navigating through the system. Self-referral systems that do not take this into account are likely to increase inequalities of access and outcome.

## Action needed

- Review assessment procedures and ensure system that offers regular review is in place.
- Develop protocol or mechanism to ensure care plans are joint, for example using the Single Assessment Process, and consider carers' needs.
- Enable and support self-assessment.

## Measuring success

- Greater proportion of people reviewed at six weeks, six months and one year
- Greater proportion of carers receiving assessments

## QM15. Participation in community life

### Marker of a quality service

- People who have had a stroke, and their carers, are enabled to live a full life in the community.

### Rationale

42. Many people who have had a stroke, and their carers, want to be able to return to varied roles they had before a stroke and to be involved in their local communities again.<sup>63,64</sup> Long-term assistance, review and rehabilitation are essential if people are to lead autonomous lives and overcome physical, psychological and attitudinal barriers and to engage and participate in community activities. To maximise emotional recovery, people need information and advice about local opportunities and resources, including clubs, hobbies, leisure, education and sports facilities.
43. Studies looking at leisure activities for people who have had a stroke found that there were numerous clubs, societies, specialist equipment and written information leaflets available, but that people needed someone to get them started or help them return after a break due to a stroke.<sup>65</sup> Allied health professionals, in particular, can support individuals and carers in initiating the appropriate links and can work in partnership with local community and voluntary sector organisations to enable sustained inclusion and participation. Opportunities for peer support can also enable and empower individuals, especially in relation to rebuilding the confidence that many people with stroke lose.
44. Local services may also need to adapt to meet the specific needs of people who have experienced a stroke. Stroke specialists, particularly allied health professionals and the voluntary sector, are well placed to provide occasional advice and training to a wide

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<sup>63</sup> Parker CJ, Gladman JR, et al., 1997, 'The role of leisure in stroke rehabilitation', *Disability and Rehabilitation*

<sup>64</sup> Han B and Haley WE, 1999, 'Family caregiving for patients with stroke: review and analysis', *Stroke* 30, 1478–85

<sup>65</sup> Drummond AE, and Walker MF, 1995, 'A randomised controlled trial of leisure rehabilitation after stroke', *Clinical Rehabilitation* 9, 283–90



range of community providers to enable them to make their activities and opportunities more accessible to enhance participation. Physical access will be important, but local authorities should consider the wider needs of those who have communication and cognitive difficulties following a stroke.

- 45.** Stroke causes a range of difficulties that can prevent people from driving, so people with stroke and their carers may be more reliant on using public transport or locally available transport schemes. However, using public transport can pose its own problems for people with stroke, particularly those with physical, communication and cognitive difficulties. For those wishing to return to driving, mobility centres across the country can provide an assessment of ability to drive or advice on adaptations required to enable someone to return to driving if prevented by a physical impairment.<sup>66</sup> Advice is also available for a person who has had a stroke, or a carer, on modifications to aid access to the vehicle.

## Action needed

- Local authorities to look at accessibility planning and how they meet the needs of those who have had a stroke, for example through their local transport plans process.
- Stroke specialists to provide training to providers of community services. Commissioners should also consider providing training on stroke to a wider range of organisations that come into contact with individuals who have had a stroke, for example care home staff. Allied health professionals and stroke voluntary organisations are particularly well placed to carry out this training.
- Review of information provision.
- Ensure that there are a range of services available locally for people to choose from when agreeing their care plan.

## Measuring success

- Positive response to service-user survey on their views of service provision

## QM16. Return to work

### Marker of a quality service

- People who have had a stroke and their carers are enabled to participate in paid, supported and voluntary employment.

## Rationale

- 46.** Studies show that work is good for physical and mental health.<sup>67</sup> The inter-relationship between health, work and well-being was recognised by the *Commissioning Framework for Well-being*.<sup>68</sup> The workplace allows people both economic benefits

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<sup>66</sup> For more information see [www.mobility-centres.org.uk](http://www.mobility-centres.org.uk)

<sup>67</sup> Waddell G and Burton KA, 2006, *Is work good for your health and well-being?*, London, The Stationery Office

<sup>68</sup> Department of Health, 2006, *Commissioning Framework for Health and Well-being*, London, DH

and valuable social relationships. Many workplaces could offer simple, reasonable adjustments to enable people who have had a stroke to return to work, and are required to do so under the Disability and Discrimination Act 1995.

47. The workplace is also one of the best forms of rehabilitation.<sup>69</sup> Many people who have had a stroke will not be ready to return to work in the short term, but may be able to do so in the longer term and so can benefit from arrangements to give access to rehabilitation and support for return to work weeks, months or years post-stroke, as appropriate for the individual. There is evidence that this can be achieved by offering vocational rehabilitation to people after a stroke, and this may need to begin when they are in hospital.<sup>70</sup> It will also include access to government schemes for return to work. Volunteering can also provide both a means of trialling return to work and a satisfying alternative to paid employment for some people. Connect provides guidance about volunteering both for people with stroke and for voluntary organisations who want to involve volunteers with stroke and aphasia.<sup>71</sup>
48. Carers may also need support either to return or continue to work. In April 2003, the Government introduced a new right for parents of children up to age six and disabled children up to 18 to request flexible working and put a duty on the employer to consider their request seriously. The Work and Families Act extends the right to carers of adults from April 2007.
49. It may also be important to offer support for employers and voluntary organisations in adapting working conditions, especially for people with physical, communication and cognitive difficulties. This may include offering guidance on how to educate co-workers about the condition and what it means in practice for the individual's role in an organisation. Alternatively, support may be needed to facilitate, for example, reduced hours, and part-time working initially.
50. This marker is supported by quality requirement 6 of the *National Service Framework for Long-term Conditions*: 'vocational rehabilitation'.

## Action needed

- Ensure support is offered to both individuals and their carers to enable them to return to work or to other opportunities such as volunteering.
- Establish partnership with Pathways to Work locally.

## Measuring success

- Greater proportion of individuals and carers who return to paid work
- Greater proportion of individuals and carers volunteering

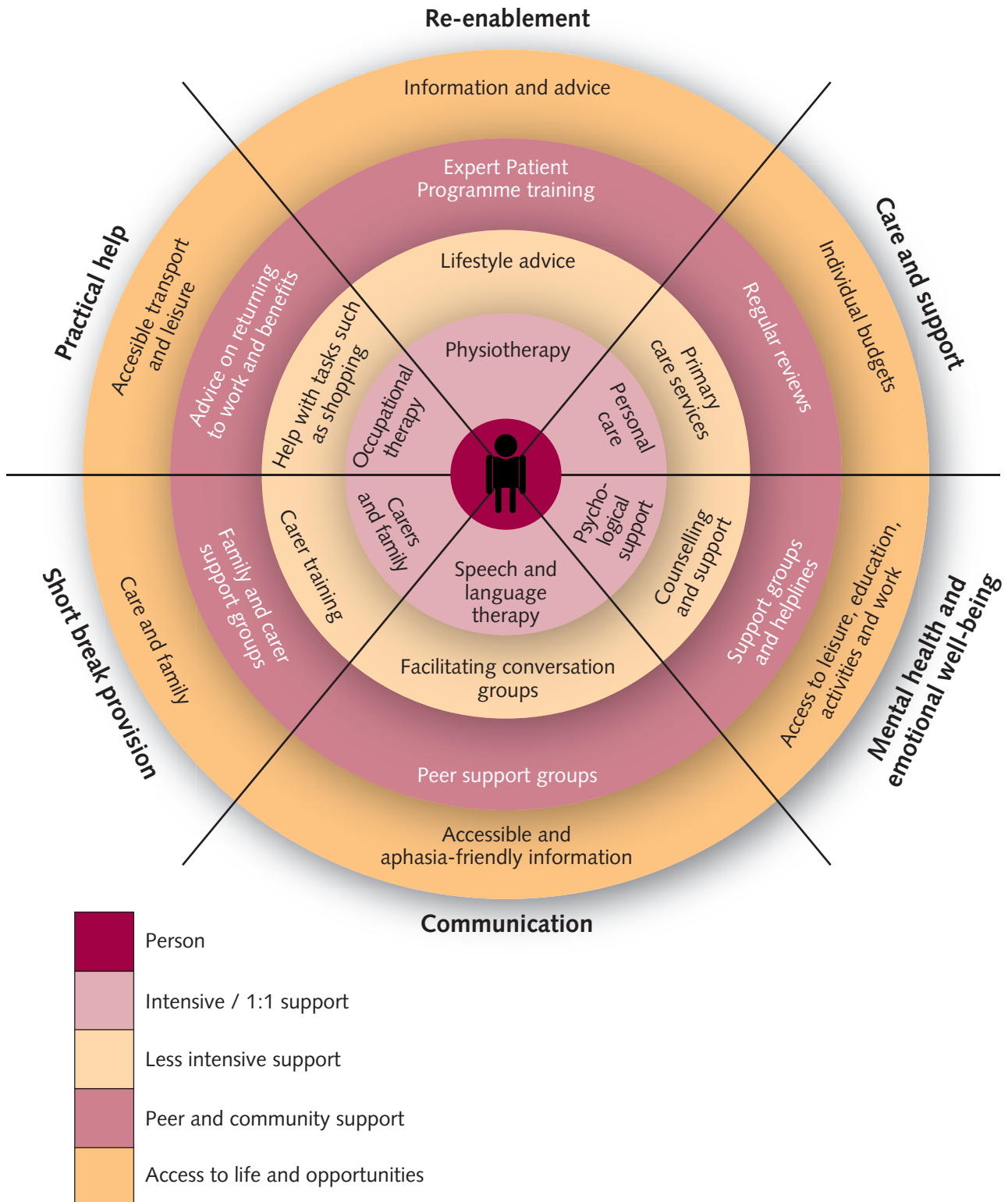
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<sup>69</sup> Waddell G and Burton KA, 2006, *Is work good for your health and well-being?*, London, The Stationery Office

<sup>70</sup> Jordan L and Bryan K, et al., *Work after stroke: Stroke survivors' perspectives*, UK Stroke Forum Conference, Harrogate

<sup>71</sup> Available from [http://www.ukconnect.org/publications\\_26\\_316.aspx](http://www.ukconnect.org/publications_26_316.aspx) and [http://www.ukconnect.org/publications\\_27\\_317.aspx](http://www.ukconnect.org/publications_27_317.aspx)

## The range of support someone may need after a stroke



# Chapter 4

## Working together



### Aims

1. To have structures in place which ensure a focus on quality of services and continuous service improvement, across all the organisations in the pathway.
2. To grow a workforce that enables all people with stroke, and at risk of stroke, to receive care from staff with the appropriate level of knowledge, skills and experience.

### Key facts

- A survey of 92 stroke units conducted by the Department of Health (DH) and Royal College of Physicians (RCP) suggested that for hospital care, only 25 per cent of units had adequate staff numbers for nursing care and rehabilitation.<sup>72</sup>
- Not all individuals requiring rehabilitation receive it, with 75 per cent getting less than an hour of physical therapy input per day, limited to daytime hours and weekdays.<sup>73</sup>
- Only one in four units have access to clinical psychology services.
- 75 per cent get less than 4 hours of nursing input each 24 hours.<sup>74</sup>
- UK staff have less contact time with individuals, compared with other countries.<sup>75</sup>

### Introduction

3. High-quality care and services for people with stroke or at risk of stroke need to be delivered by staff with stroke specialist knowledge. The challenge is to ensure capability, capacity, and collaborative working both within stroke teams and across providers and commissioners so that there is an overall focus on delivery of high-quality stroke care and services.

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<sup>72</sup> Department of Health and Royal College of Physicians, 2007, *Survey of Stroke Unit Staffing and Patient Dependency*, London, DH

<sup>73</sup> Ibid.

<sup>74</sup> Ibid.

<sup>75</sup> Lincoln N, 2005, 'Collaborative Evaluation of Rehabilitation in Stroke across Europe (CERISE)', *National Research Register*, Issue 3

## QM17. Networks

### Marker of a quality service

- Networks are established covering populations of 0.5 to 2 million to review and organise delivery of stroke services across the care pathway.

### Rationale

4. Networks for stroke have real potential to improve the way that services are planned and delivered for both individuals with stroke and staff. Health and social care members of a network may agree to work together or share information, functions and resources in order to offer services or improve their efficiency and quality of service. Organisations join networks because they can do what they need to do more effectively together than if they operate alone. Eight stroke research networks have been formed, covering 70 per cent of the population of England, but there are few wider networks among providers that might take an overview and consider how to address shortfalls in provision.
5. For networks to be effective, they need to make the whole care pathway a reality. Rather than a series of disconnected episodes of care from apparently disjointed services, the individual can experience co-ordinated care from first contact services, primary, secondary and tertiary NHS care, also extending into social care, housing and the voluntary sector. This is particularly important in planning discharge from hospital and then support in the community. It is also important to involve individuals who have had a stroke and their carers in this process.
6. Commissioning networks across health and social care can also be beneficial. Not every primary care trust or local authority can be expected to have staff with the relevant expertise in commissioning stroke services for their resident population, and it is complex for providers to work with multiple commissioners. More efficient commissioning would be provided by commissioning groups, co-ordinated and advised by the network, with one primary care trust taking a lead on stroke.
7. Experience in other services, such as those for coronary heart disease and cancer, has demonstrated how networks can enhance service quality and support continuous service improvement. Networks can support development in individual services as well as improve co-operation and co-ordination. This latter function is essential to guarantee prompt, safe, and efficient delivery of high-quality care. Increasingly it is becoming impractical for organisations to offer care pathways that are safe, of high quality and responsive to individuals without being part of well-defined networks.
8. Networks will want to look at acute 24-hour specialist care, including thrombolysis, rapid admission to acute stroke units and acute and subsequent rehabilitation. As outlined in *Mending Hearts and Brains*, it will not be possible for every emergency department to have the specialist staff necessary to enable the fast response to stroke that is needed.<sup>76</sup>

<sup>76</sup> Department of Health, 2006, *Mending Hearts and Brains*, London, DH



The development of networks for stroke serving a population of between 0.5 and 2 million, organised in a 'hub and spoke' service model, is one solution. A hyper-acute stroke unit (hub) would have an on-site, 24-hour acute stroke team with 24-hour radiology access, including advanced imaging. People who have had a stroke receiving hyper-acute care could be transferred to a 'spoke' acute stroke unit within 48 hours. Some spokes may provide specialist services, but not 24/7. Each network would need to agree access to neurointensivist care for certain conditions (see Chapter 2, 'Time is brain').

9. 'Virtual Networks', where people are seen, assessed and imaged at local district general hospitals with appropriate teleradiology and telemedicine support, are also a possibility, particularly in rural areas. Selected complex cases would transfer to a hyper-acute centre in this model.
10. Guidance and help with stroke care network development will be provided at a local and national level. At local level, cardiac networks will be a key support and ally for stroke networks, with many already discussing potential joint working with stroke colleagues. At national level, the Heart Improvement Programme (HIP) and DH are working to establish a team to provide specific support to develop stroke networks, supplementing that available locally. This team will also offer national forums to the community of networks and facilitate links with DH.

## Action needed

- Establish a stroke care network that includes all relevant organisations involved in the care of individuals with stroke, such as:
  - ambulance services
  - primary care trusts
  - primary care providers
  - acute NHS trusts
  - mental health trusts
  - local authorities – in particular the adult social care team, but also housing services
  - voluntary sector providers
  - voluntary sector representative organisations and/or representation from people who have had a stroke and their carers
  - community transport services
  - strategic health authorities
  - specialised services commissioners.
- Develop a work plan for each stroke care network that includes the key elements of network functioning – enhancing co-operation between individuals and organisations, service improvement, and supporting commissioning.
- Establish a central team to co-ordinate and support stroke network development.



## Measuring success

- Local network includes primary care trusts, local authorities, NHS provider trusts, ambulance services, voluntary sector providers and representatives, and representation of individuals who have had a stroke
- Objectives of the network are agreed and an action plan is in place
- Stroke care pathway is agreed

## QM18. Leadership and skills

### Marker of a quality service

- All people with stroke, and at risk of stroke, receive care from staff with the skills, competence and experience appropriate to meet their needs.

### Rationale

11. High-quality care and services to people with stroke or at risk of stroke should be delivered by inter-professional and inter-agency teams who are competent in their own roles and have stroke expertise, understand the roles of others and their key activities, and are able to support activities of other staff when required. This applies to all practitioners in all of the different settings relevant to stroke and at all stages of the stroke care pathway.<sup>77,78,79</sup>
12. Existing staffing numbers and skill mix profiles are insufficient to deliver the required input in stroke care pathways. Workforce review is therefore needed, along with a workforce plan that defines the care pathway, lists the functions at each stage and the competencies required to perform the functions, and then ensures training is put in place to support staff to acquire the competencies.

### Action needed

- Managers of staff need to:
  - Use core competences for all healthcare staff working with people with stroke, including in non-specialist areas (e.g. those created by the Scottish Health Board).
  - Use the National Occupational Standards for Stroke to underpin the design and redesign of roles, as a mechanism for ensuring the delivery of high-quality care and services to people with stroke or at risk of stroke.
  - Ensure areas and levels of competences are consistent with employers' reward systems.

<sup>77</sup> Williams, et al., 1993, 'Do Stroke Units Save Lives?', *Lancet* 342, 8868

<sup>78</sup> Stroke Unit Trialists' Collaboration, 1997, 'Collaborative systematic review of the randomised trials of organised inpatient (stroke unit) care after stroke', *British Medical Journal* 314, 7088

<sup>79</sup> Langhorne P, et al., 2005, 'Early supported discharge services for stroke patients: a meta-analysis of individual patients' data', *Lancet* 365, 501–6

To do this, commissioners may need to:

- ensure effective leadership, which is the best way to deliver change in the improvement of stroke service, with engagement on stroke services at board level. Leaders will need to ensure they consider service development roles and the potential for people with stroke and their carers to play a role in transforming services, for example as inspirational role models.
- have an identified person to be responsible for leading service delivery and development, including development of staff, as well as developing mechanisms for, and an ethos of, shared responsibility.
- consider new and more flexible roles (i.e. expanding roles across professional boundaries), to ensure professional development opportunities and to support their staff with the availability of evidence, standards and guidelines and protected learning time. Case studies showing new roles, new ways of working and extension of existing roles are being published on the DH website with this strategy.
- initiate competence-based training for the extension of roles, the development of generic skills (IT, research) and consideration of competences for non-specialist staff.
- link grading to the NHS Knowledge and Skills Framework and to the Stroke Specialist Competence Framework.<sup>80</sup>
- design and redesign roles underpinned by National Occupational Standards.
- involve people who have had a stroke and their carers in training of providers.
- provide high-quality information and training to help non-specialist staff, especially social care staff, deal more effectively with stroke.
- develop re-enablement and vocational rehabilitation schemes.

Strategic health authorities may need to:

- work together with primary care trusts, deaneries, higher education institutions and provider organisations to facilitate the introduction of major workforce innovations and encourage the development of deaneries with a multi-professional focus.
- consider all relevant stroke service settings: independent, voluntary sector, hospital, home and community.

## Measuring success

- Greater proportion of stroke services staff who have received stroke leadership training
- Greater proportion of stroke services staff who have undertaken stroke research network training
- Greater proportion of staff who have taken undergraduate or postgraduate courses in stroke care
- Greater proportion of staff who have taken research degrees (MPhil, PhD, MD) or post-doctoral fellowships
- Greater proportion of staff who have undertaken the RESPONSE on-line training course

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<sup>80</sup> Available at: [www.skillsforhealth.org.uk](http://www.skillsforhealth.org.uk)

## QM19. Workforce review and development

### Marker of a quality service

- Commissioners and employers undertake a review of the current workforce and develop a plan supporting development and training to create a stroke-skilled workforce.

### Rationale

13. Existing staffing numbers and skill mix profiles are insufficient to deliver the required input in stroke care pathways. Workforce review is therefore needed, along with a workforce plan that defines the care pathway, lists the functions at each stage and the competencies required to perform the functions, and then ensures training is put in place to support staff to acquire the competencies.
14. Staff working with stroke have variable levels of knowledge and skills. Specialist knowledge has developed *ad hoc* in practice and there is no nationally recognised stroke-specific training. Nationally recognised, quality-assured and transferable training and education programmes for stroke linked to professional roles and career pathways are needed.

### Action needed

- Commissioners of stroke services to review and revise existing workforce numbers and profiles, or commission new ones, based upon a local population needs assessment and taking account of DH guidance and that from the workforce review team.
- Commissioners to ensure diversity in the workforce to meet the needs of different parts of the community, and to promote equality of opportunity of work.
- Commissioners to invest in posts and training to develop the stroke workforce in leadership, managing change and modernising services.
- Investment in teaching and academic posts in stroke to provide teaching for undergraduates and postgraduates, and to address the shortfall in stroke research.
- Deaneries, higher education institutions and strategic health authorities to work with commissioners to provide authoritative analysis of local workforce needs, to ensure there are effective supply mechanisms for key workforce groups and to facilitate major innovations in the local multi-professional workforce.
- Strategic health authorities to monitor equity across their area, ensuring effective supply and quality assurance mechanisms for learning.
- All staff involved in stroke care and patient education to demonstrate the relevant skills and competencies for effective communication/information provision.

## Resources to support workforce planning

Stroke units in England have contributed to a snapshot survey of staffing levels, including views on aspirational staffing levels related to dependency levels. Medical, nursing and allied health professionals concerned with stroke care have prepared statements endorsed by their professional organisations on current staffing issues and staffing requirements. These statements, together with material from the Sentinel Audit, the Stroke Unit Trialists' Collaboration and case studies on new roles, new ways of working and extension of existing roles are collated on the DH website as a resource for commissioners and employers.

Once stroke is diagnosed, key staff involved in treatment and care are stroke physicians, stroke nurses, physiotherapists, speech and language therapists and occupational therapists, but many members of other allied health professions and other health, social care and voluntary organisations staff also have an important role. A list of these is also available on the website.

The Workforce Review Team is carrying out a project to analyse gaps in staffing levels and required staffing increases, based on current workforce configuration and new and/or re-designed roles which will be available to support commissioners and employers in their workforce planning early in 2008.

Additionally, NHS National Workforce Projects has been commissioned to develop a workforce resource pack to support implementation of the National Service Framework for neurological long-term conditions. The resource pack will be ready to launch in spring 2008. It will:

- demonstrate the contribution workforce development and effective workforce planning can make to implementation of the NSF;
- influence and support commissioners' decision-making;
- demonstrate the clinical impact and cost-effectiveness benefits that new ways of working can have in delivering care, including the impact of having practitioners with specialist expertise in neurological conditions; and
- demonstrate the value of third sector local partnerships in improving the quality of services.

## Measuring success

- Evidence that a local needs assessment has been done and commissioners and employers have data on numbers of different types and skill mix of staff on acute and rehabilitation units, in early supported discharge teams, and in community teams
- Number of key jobs where job evaluation and grading is underpinned by stroke-specific National Occupational Standards and linked to the Knowledge and Skills Framework
- Greater proportion of stroke-specialist trained staff
- Workforce action plan in place

## QM20. Research and audit

### Marker of a quality service

- All trusts participate in quality research and audit, and make evidence for practice available.

### Rationale

15. Provision of evidence-based services and participation in the development of research evidence for practice are key tenets of high-quality stroke service provision. The Stroke Research Network aims to facilitate stroke research by bringing about focused, effective investment to enhance NHS research infrastructure for stroke, and to increase collaborative working between academics, stroke clinicians, stroke service users and research funders. Local development of a co-ordinated infrastructure, including a workforce with the capacity and capability to participate is key.
16. The RCP National Sentinel Audit of the organisation of stroke care and its clinical audit has been carried out in two-yearly cycles since 1998. This enables providers to benchmark the quality of their services and assess progress on delivery of national guidelines and standards.

### Action needed

- Strategic health authorities, providers and commissioners of services may need to:
  - ensure participation in high quality research, and audit.
  - consider roles, and ensure relevant research focuses on professional development.
  - ensure access to training for staff wishing to participate.
  - ensure user/carer involvement in setting priorities for participation in research.

### Measuring success

- Development of links with local research networks for stroke
- Greater proportion of staff participating in UK Clinical Research Network, Stroke Research Network and local research network research training
- Greater proportion of staff with undergraduate, and/or postgraduate education and training in research
- Greater proportion of staff completing good clinical practice (GCP) training (in research)
- Greater proportion of patients recruited into trials, and other well-designed studies adopted by the Stroke Research Network
- Review knowledge of evidence for practice of staff
- Evidence of patient and public involvement mechanisms
- All trusts participating in the RCP Sentinel Audit

# Chapter 5

## National support for local implementation



### Introduction

1. Chapters 1 to 4 set out markers of a good quality service. Their purpose is to assist those responsible for planning and delivering services in ensuring that these improve over the next ten years. This chapter signposts the national support that is currently available or being developed to support the delivery of these improvements.
2. Stroke cuts across the national agenda, requiring input and commitment to make the necessary improvements, not just from people who deliver services at the front line, but also from the infrastructure underpinning the health and social care system. Stroke is relevant to almost every aspect of the health and social care system, and beyond, from the important support and care provided by social care once a stroke has happened to intensive and specialised treatment in hospital, and even to the prevention of strokes through wider support for healthy living. Good care is complex, but we know that it is feasible because there are already areas where good practice flourishes. As one of the major diseases, stroke represents a key opportunity to realise the benefits of features that the NHS and social care systems have been developing in recent years, such as the Payment by Results mechanism and the primacy of commissioning.

### Development of networks

3. The strategy identifies networks as a clear lever for change. The shape of local networks and their day-to-day agendas will be determined by the networks themselves. To support local networks the Department of Health (DH) is establishing a central team within the NHS. This will build on the successful experience of the Heart Improvement Programme (HIP).
4. The main task of this team will be to ensure that specific support is available to develop stroke networks to supplement those available locally. This will be implemented through a number of initiatives and structures such as:
  - training and development for stroke network staff, including clinical leaders within networks;



- co-ordinating regional and national fora for stroke network staff;
  - organising improvement events and conferences for stroke networks to ensure shared learning and understanding of national perspectives;
  - providing a communication system to help sharing of learning from network improvement activities;
  - co-ordinating and supporting network involvement in key priority projects underpinning implementation of the stroke strategy.
5. Co-ordinating work in national priorities will be based on experience from cardiac and other network areas, where concerted efforts by many networks can accelerate the implementation of new policies or clinical innovations.
  6. National initiatives will also promote peer support within the community of stroke care networks. Cardiac and cancer networks have benefited from clear and effective communication links to national clinical leaders and DH, and a similar system will be established for stroke networks.

## Demonstration sites

7. We will also seek to develop demonstration sites which enable us to not only show a step change in service provision in those areas, but to provide lessons that can be shared. These sites will cover both acute and community services.

## Workforce

8. DH has already supported the development of the skills of the stroke workforce, through the development of leadership courses, training tools for first contact staff, nurse training and the funding of 13 additional stroke physician posts. We will continue to support a programme of work that develops stroke physicians, nurses and allied health professionals, and to identify and inspire the stroke leaders of the future.
9. DH has been liaising with professional organisations, the NHS Workforce Review Team and the Stroke Association to establish a National Training Forum to provide for the need for nationally recognised, quality-assured and transferable education and learning programmes in stroke at pre-registration and post-graduate level. This forum will also be responsible for linking training and education to competences, professional development and career pathways.
10. National Occupational Standards and Skills for Health stroke specialist competence frameworks are being developed. Basic National Occupational Standards are complete and can be found on the Skills for Health website. They can be used to underpin the design and redesign of roles and as a mechanism for ensuring the delivery of high-quality care and services to people with, or at risk of, stroke. Further work on more specialist competences such as thrombolysis for stroke are in preparation.

11. As part of the overall strategy, DH has published a workforce resource pack online, which contains statements from professionals' groups, examples of job redesign, and data from a survey of stroke units conducted in 2007 as well as other data on staffing levels to assist local workforce planning. Additionally, the Workforce Review Team is carrying out a project to analyse gaps in staffing levels and required staffing increases based on current workforce configuration and new and/or re-designed roles. This will be available to support commissioners and employers in their workforce planning early in 2008.
12. Stroke care is being considered as part of DH's review of curricula in undergraduate and post-graduate training with professional and regulatory bodies.

## Awareness raising

13. Awareness of stroke amongst the public and health and care professionals is low, and DH will act to co-ordinate awareness raising at a national level. Related communications strategies (e.g. obesity prevention) will need to provide consistent messages. Consideration will be given as to how to ensure the message is delivered to those most at risk.

## Commissioning

14. In December 2006 DH published *Improving Stroke Services: a guide for commissioners*, on the key issues to consider in ensuring a good quality stroke service, and a version of ASSET to support commissioners in decision-making.
15. *The Commissioning Framework for Health and Well-being* is designed to enable local authorities, primary care trusts and practice-based commissioners to work together more effectively to provide services that are tailored to the needs of individuals and local communities, and to help people maintain their health, well-being and independence wherever possible.<sup>81</sup>
16. DH is now working to help the NHS move towards world-class commissioner status by improving commissioning capability. This will transform the way we commission health and care services in the NHS. It will mean a shift from traditional models of commissioning to developing new, innovative partnerships to deliver local health services. The world-class commissioning programme will see the launch of a vision document, which will identify what it means to have world-class status and the set of competencies needed to achieve it. Delivery of the vision will take place within an assurance system. This will drive performance and development, and reward commissioners as they move from their current position towards world-class status. A support and development framework will be available early next year to provide primary care trusts with the tools they need to drive improvements.

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<sup>81</sup> Department of Health, 2006, *Commissioning Framework for Health and Well-being*, London, DH

17. DH is working with the National Specialised Commissioning Group to ensure that appropriate arrangements are in place for commissioning specialist neurointensivist care, including interventional neuroradiology and neurosurgery.
18. The Local Government and Health Improvement Act proposes the introduction of a new duty on both primary care trusts and upper-tier local authorities to work together to carry out a joint strategic needs assessment. This will help local authorities, primary care trusts and practice-based commissioners to better understand the needs of individuals and communities, and help shape their local commissioning priorities. Local Area Agreements will bring together local partners to promote health, well-being and independence. DH is developing, in partnership with Communities and Local Government, a performance framework focused on local priorities and based on outcomes. This will be an excellent vehicle for helping local communities to establish a baseline and develop their stroke services with a strong evidence case.

## Supporting individuals and carers

### Carers

19. DH is currently consulting on a review of the Carers' Strategy *Caring for Carers*, published in 1999, as part of the New Deal for Carers. This review will consider ways in which commissioners and providers can further support those acting in a caring role. Extensive consultation with carers has raised a number of significant issues around support for carers as individuals themselves, ensuring that their health does not deteriorate and subsequently impact on their caring role. In addition, greater recognition for carers from health professionals and the government as a whole is vital for the support of carers. £25 million has already been provided to local authorities in England to provide short-term cover for carers in emergencies. The *New Deal for Carers* also includes a single telephone advice line and expert carers' programme, due to come online in summer 2008 to provide greater support to carers in their caring role.
20. The Carers' Grant was introduced in 1999 to support councils in providing breaks and other services for carers in England. The grant has provided an extra £820 million since 1999. It is worth £185 million in 2007/08, which will mean that by 2008, we will have invested over £1 billion in support for carers. The Carers' Grant is set to continue in the next spending review period.

### Employment

21. The Department for Work and Pensions (DWP) is aware of the requirement to provide better information about eligibility for other benefits to new customers claiming Employment and Support Allowance when this is introduced in Autumn 2008, and are currently working on the business design and IT to make sure that this is addressed. In addition, 'information prescription' pilots, designed to give people receiving a diagnosis of illness from a doctor more information about benefit entitlement and demonstrate how local partnerships can be effective in supporting

individuals, are currently under way. DWP, along with DH, is looking at how to improve employers' awareness of the benefits of employing people who are on incapacity benefit, overturn employers' negative preconceptions about people with disability and improve employment outcomes for people on this benefit. Accessibility of this information to people with communication and cognitive difficulties will be important, as will acknowledgement of the needs of people with these difficulties even in the absence of physical difficulties.

22. Pathways to Work, which provides support to help people claiming incapacity benefit back into or closer to the labour market, is currently being rolled out and will cover the whole country by Spring 2008. One of its requirements will be to continue to have a condition management programme available for incapacity benefit and/or employment and support allowance customers. The condition management programmes in the current Jobcentre Plus Pathways to Work districts are a collaborative effort between primary care trusts and Jobcentre Plus. Their aim is to help people to understand and cope with their health conditions or disabilities.

## Housing and support

23. Communities and Local Government is looking at improvements to the Disabled Facilities Grant (DFG) delivery to make the grant more responsive to the needs of individuals. A public consultation on the Government's proposals to improve the DFG programme was held between 18 January and 13 April 2007.
24. Following the consultation, the Government intends to reduce the bureaucracy involved in the application process and the restrictive ring-fence on funding in order to improve delivery. Creating greater flexibility would enable DFG to be used for associated purposes such as moving home, where this is a more appropriate solution. In addition, authorities will be able to simplify the system and deliver small-scale adaptations more quickly, for example, by developing a service that rapidly deals with inaccessible housing and the need for quick discharge of people from hospital.
25. In June 2007, Communities and Local Government published a strategy to improve the Supporting People programme. This strategy sets out plans to:
  - ensure that service users are at the heart of the programme and service delivery;
  - increase the support to service providers, including helping smaller providers to compete fairly for contracts to deliver services;
  - give greater freedom and support to local authorities to make Supporting People work well in their area; and
  - research and disseminate information on the most cost-effective ways of delivering services.

## Transport

- 26.** The Department for Transport, in consultation with stakeholders, will be developing and delivering a strategy for enhancing travel training across England. This will help provide disabled people and others with increased confidence and the skills to access and use public transport.

## Prevention

- 27.** Risk factors for stroke include high blood pressure and high cholesterol levels, which relate to lifestyle factors such as smoking, exposure to second-hand smoke, poor diet, excessive body weight, and low levels of physical activity. Identifying risk factors for individuals and then supporting behavioural change could lead to a reduction in the number of strokes and recurrent strokes. Key areas to tackle, then, include encouraging smoking cessation, promoting healthy eating and exercise, and reducing obesity. The risk factors for stroke can be minimised by encouraging healthy lifestyle habits, healthy eating and appropriate levels of exercise from early childhood onward. The National Healthy Schools Programme (NHSP) engages everyone – staff, pupils, governors, parents and the wider community – in a whole-school approach that aims to improve educational achievement, health and emotional well-being, and make schools a safe, secure and healthy environment in which young people can learn and develop. Over 90 per cent of schools are participating in the programme, and around a quarter have achieved the new Healthy School status.
- 28.** The bans on smoking in public places, which came into effect on 1 July 2007, and on the sale of tobacco to children under the age of 18, which came into effect on 1 October 2007, were designed to discourage individuals from smoking and to limit the exposure of others, including children and young people, to second-hand tobacco smoke. DH's Tobacco Programme includes investment in NHS Stop Smoking Services, hard-hitting media campaigns, new stark pack warnings, banning tobacco advertising, promotion and sponsorship, and other initiatives as part of a six-strand strategy. The National Support Team for Tobacco helps to increase the effectiveness of the NHS Stop Smoking Services and provides practical guidance for local implementation of tobacco control policy, while national campaigns raise awareness.
- 29.** Future actions include an expansion of more publicly accessible services, for example, in clubs, pubs and community centres. We will develop pilots on using the electronic booking system to trigger advice for smokers on stopping, with a view to national roll-out.
- 30.** Healthy eating also plays a part in preventing stroke. Around 20 per cent of strokes are due to fruit and vegetable intakes of below 600g per day.<sup>82</sup> Excess salt consumption is the biggest dietary risk factor for hypertension, and is highly prevalent in the UK:

<sup>82</sup> World Health Organization, 2002, *The World Health Report 2002: Reducing Risks, Promoting Healthy Life*



26 million adults eat more than the recommended 6g of salt a day.<sup>83</sup> Consumption of fatty foods raises cholesterol, another risk factor for stroke. Through programmes such as Healthy Start (which provides vouchers for fruit, vegetables, milk and infant formula for families on low incomes) and the School Fruit and Veg Programme (which provides a free piece of fruit or portion of vegetables for every child aged 4 to 6 in school), children who might not otherwise do so are encouraged to eat more healthily. The Government has set tough nutritional standards for school food and has made increasing the take-up of school lunches a priority, including take-up of free school meals so that as many children as possible, and especially those who need it most, get at least one nutritious meal every school day. The 5 A DAY campaign is bringing the benefits of healthy eating to the wider population, and better nutrition education has come through the Healthy Schools environment.

31. A future project based in convenience stores in deprived areas will encourage stocking healthier foods, especially fruit and vegetables, so that people from poorer socio-economic groups will have greater access to a healthier diet. The Food Standards Agency (FSA) is currently running a national campaign on lowering salt consumption. The campaign specifically highlights the higher risk of stroke from consuming excess salt, as well as advising on correct daily levels. The FSA has also developed a model of front-of-pack labelling using a traffic light colour code to indicate whether levels of fat, saturated fats, sugar and salt are high, medium or low.
32. Unhealthily high body weight and lack of physical activity both increase blood pressure. The Government is encouraging the habits of sufficient, appropriate exercise in individuals from an early age. Currently, 86 per cent of school pupils are doing at least two hours of high-quality physical education and school sport in a typical week – up from an estimated 25 per cent in 2002. In addition, the Government wants more opportunities for 5–19-year-olds to participate in a further three hours of sporting activities through attractive provision designed to stimulate and increase take-up and sustain participation. Walking and cycling to school are important ways of bringing exercise into children's – and parents' – daily routine, with potential health and environmental benefits. The Government wants all schools in England to develop sustainable travel plans and has already paid out more than £55 million in capital grants to the 10,000 schools with plans.
33. Reducing obesity across the population is a key Government priority. The recent Foresight report, *Tackling Obesities: Future Choices*, makes clear that, in tackling obesity, we are facing a global problem on the scale of climate change. Government has been reviewing its approach alongside the development of the Foresight report and will develop a comprehensive cross-government strategy.

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<sup>83</sup> Food Standards Agency, 2007, [www.salt.gov.uk/the\\_salt\\_you\\_eat.html](http://www.salt.gov.uk/the_salt_you_eat.html)



## Research

34. Implementation of the government's health research strategy, *Best Research for Best Health*, is creating significant new opportunities for stroke research in the NHS and for the integration of research with service delivery.
35. DH has committed £20 million over five years to support the UK Stroke Research Network. The Network was launched in 2005 as part of the UK Clinical Research Network. It will provide a world-class health service infrastructure to support clinical stroke research and will remove barriers to conducting this research. The primary aim of the network is to facilitate clinical trials and other well-designed studies, some 40 of which, concerned with acute care, prevention, primary care and rehabilitation, are already in progress or planned.
36. The Stroke Research Network works closely with patients, their carers and the public to ensure their involvement at all levels of its activity.
37. We have commissioned a short analysis of research evidence in relation to the stroke strategy and the preliminary top ten areas for new research are listed below. We will make this report available and hope that it will be useful both to researchers and to those funding research.

### Top ten priorities for stroke services research

1. Identification of the key components needed for an effective campaign aimed at reducing the delay in diagnosing and managing stroke. The campaign should then be piloted in different groups of the population.
2. Identification of the key components of acute care, including key competencies of staff, that lead to improved outcomes, and subsequent piloting of systems to test how these can be most effectively implemented in routine clinical practice. If new models of care such as specialist hyper-acute stroke centres are developed, the impact on the rest of the stroke pathway will need to be evaluated.
3. A trial of the cost and clinical effectiveness of admission to general medical (acute admission) wards with onward referral to a stroke unit, compared with direct admission to a stroke unit. This is needed, given that currently 80 per cent of stroke patients are admitted to acute admission wards.
4. Evaluation of different models of access to Transient Ischaemic Attack (TIA) services in different settings, e.g. direct access to daily clinics in secondary care versus immediate assessment and management in primary care with onward referral to secondary care.

5. Estimation of the longer-term needs of patients (impairment, activity, participation, quality of life) at different time points post-stroke to help direct intervention studies to improve outcomes.
6. Evaluation of the effectiveness of rehabilitation interventions after the acute phase of stroke and into the longer term. The key areas for evaluations should include:
  - key components of effectiveness;
  - optimum content (techniques, treatment approaches, assistive technologies);
  - optimum delivery (frequency, duration, timing); and
  - optimum structure (service provision and economic benefits).
7. Identification of the relationship between patient numbers, dependency and staffing requirements, with a view to providing more specific guidance on the appropriate staffing numbers and skills.
8. Evaluation of the principle of extending specialist stroke unit care into the community. For example, a Medical Research Council framework approach to identifying the building blocks is required.
9. Identification of how the training needs of stroke professionals can best be met.
10. Development of comprehensive outcome measures for stroke that can be universally adopted by the stroke community.

## Audit

38. The Royal College of Physicians' (RCP) National Sentinel Audit of the organisation of stroke care and clinical audit has been carried out in two-yearly cycles since 1998. This enables providers to benchmark the quality of their services and assess progress on delivery of national guidelines and standards. The RCP audit of stroke services currently focuses on the acute sector. Work is under way to consider whether this audit could be extended to primary care and community services.
39. The White Paper *Trust, Assurance and Safety*, published in February 2007, announced a reinvigoration of clinical audit.<sup>84</sup> The National Clinical Audit and Patients' Outcomes Programme (NCAPOP), which funds the National Sentinel Audit, will be expanded, with its functions increased to include a clinical audit forum for wider engagement with stakeholders, a web-based library of tools and guidance and development of topics and methods for local audit that augment and complement national audit. A National Clinical Audit Advisory Group will be established to act as a steering group to the

<sup>84</sup> Department of Health, 2001, *Trust, Assurance and Safety – The Regulation of Health Professionals in the 21st Century*, London, DH

NCAPOP, and to provide advice and recommendations to DH on clinical audit matters. These new arrangements will take effect early in 2008.

## Stroke imaging

40. DH is working with appropriate professional organisations and experts in the field to publish a guide to stroke imaging.

# Annex A

## Glossary



**ABCD2 system** – The ABCD2 score is calculated using the patient's age (A); blood pressure (B); clinical features (C); duration of TIA symptoms (D); and presence of diabetes (2). Scores are between 0 and 7 points. **Age** ( $\geq 60$  years, 1 point); **Blood pressure** at presentation ( $\geq 140/90$  mm Hg, 1 point); **Clinical features** (unilateral weakness, 2 points; speech disturbance without weakness, 1 point); **Duration of symptoms** ( $\geq 60$  minutes, 2 points; 10–59 minutes, 1 point); and presence of diabetes (1 point). Low risk = 0–3 points; moderate risk = 4–5 points; high-risk = 6–7 points.

**Acute care** – Care for a disease or illness with rapid onset, severe symptoms and brief duration.

**Allied health professionals** – Allied health professionals (arts therapists, chiropodists/podiatrists, dietitians, occupational therapists, operating department practitioners, orthoptists, physiotherapists, prosthetists and orthotists, psychologists, psychotherapists, radiographers and speech and language therapists) are part of a healthcare team with a range of different skills, each bringing their particular expertise to caring for the patient. Allied health professionals have their own caseloads of patients and are key members of a skilled multidisciplinary team.

**Aphasia** – Partial or total loss of the ability to articulate ideas or comprehend spoken or written language, resulting from damage to the brain.

**British Hypertension Society** – The British Hypertension Society provides a medical and scientific research forum to enable sharing of cutting-edge research in order to understand the origin of high blood pressure and improve its treatment.

**Clinical Effectiveness and Evaluation Unit (CEEU)** – The main aim of the CEEU, which is based at the Royal College of Physicians, is to improve the quality of care delivered to patients in the NHS. The CEEU does not undertake basic clinical research but concentrates on ways of ensuring that best practice and evidence-based approaches to care are widely disseminated and used for the benefit of patients.

**Commissioners** – Commissioners are the primary care trusts, which have the responsibility of commissioning the right services for their community and providing links with GPs and local authorities.

**Commissioning** – The full set of activities that local authorities and primary care trusts undertake to make sure that services funded by them, on behalf of the public, are used to meet the needs of the individual fairly, safely, efficiently and effectively.

**Commissioning specialised services** – The first implementation plan for Sir David Carter's *Review of Commissioning Arrangements for Specialised Services* in the NHS was published in 2006. The follow-up plan outlines the significant achievements of the first year after the initial review recommendations were published and sets out the remaining challenges for the new organisations.

**Direct payments** – Payments given to individuals so that they can organise and pay for the social care services they need, rather than using the services offered by their local authority.

**Directors of Public Health** – A chief officer post in the NHS responsible for public health, Directors of Public Health monitor the health status of the community, identify health needs, develop programmes to reduce risk and screen for early disease, control communicable disease and promote health.

**Disabled Facilities Grants (DFGs)** – Grants issued by councils towards meeting the cost of providing adaptations and facilities (such as level-access showers and stair lifts) to enable disabled people to continue to remain independent in their own homes.

**Expert Carer Programme** – To support carers and those they care for, the Department of Health (DH) has announced the creation of the Expert Carer Programme. The Programme will provide training to carers enabling them to care for themselves and those they care for more effectively. DH is currently consulting the national carers' charities as to the exact nature of the programme's content, but it will reflect the diversity of roles and experiences of carers.

**Expert Patient Programme (EPP)** – The Expert Patient Programme (EPP) is an NHS programme designed to spread good self-care and self-management skills to a wide range of people with long-term conditions. Using trained non-medical leaders as educators, it equips people who have arthritis and other long-term conditions with the skills to manage their own conditions.

**FAST** – The **Face-Arm-Speech-Test**, which helps people to recognise the symptoms of a stroke or TIA in others.

**Haemorrhagic stroke** – Stroke caused by the bursting of a blood vessel leading to bleeding in the brain, which causes damage.

**Individual budgets** – Individual budgets, currently being piloted, bring together a variety of income streams from different agencies to provide a sum for an individual, who has control over the way it is spent to meet their care needs.

**Information prescriptions** – The DH White Paper *Our health, our care, our say* sets out a commitment for information prescription, improving access to appropriate information for people with health and/or social care needs.

**Ischaemic stroke** – Stroke caused by a clot narrowing or blocking a blood vessel so that blood cannot reach the brain, causing brain cells in the area to die due to lack of oxygen.

**Joint British Societies** – Comprises the British Cardiovascular Society, the British Hypertension Society, Diabetes UK, Heart UK, the Primary Care Cardiovascular Society and the Stroke Association. The aims of the society are to promote a consistent multidisciplinary approach to the management of people with established atherosclerotic cardiovascular disease (CVD) and those at high risk of developing symptomatic atherosclerotic.

**Local Area Agreement (LAA)** – A three-year agreement that sets out the priorities for a local area in certain policy fields as agreed between central government, represented by the Government Office for the Region, and a local area, represented by the local authority and Local Strategic Partnership and other partners at local level. The agreement comprises outcomes, indicators and targets aimed at delivering a better quality of life for people through improving performance on a range of national and local priorities.

**National Audit Office (NAO)** – The NAO scrutinises public spending on behalf of Parliament. It is totally independent of government and audits the accounts of all central government departments and agencies, as well as a wide range of other public bodies. It reports to Parliament on the economy, efficiency and effectiveness with which these bodies have used public money.

**National Institute for Health and Clinical Excellence (NICE)** – The independent organisation responsible for providing national guidance on the promotion of good health and the prevention and treatment of ill-health.

**NHS Direct** – NHS Direct provides 24-hour access to health information and clinical advice, via telephone (0845 46 47 in England), as well as a website (NHS Direct Online [www.nhsdirect.nhs.uk](http://www.nhsdirect.nhs.uk)) and an interactive digital TV service (NHS Direct Interactive). A printed NHS Direct healthcare guide is also available.

**NHS National Workforce Projects** – A partner agency that specialises in helping NHS organisations to achieve their workforce objectives.

**Palliative care** – Palliative/end-of-life care is the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of



palliative care are also applicable earlier in the course of the illness in conjunction with other treatments.

**Payment by Results (PbR)** – A scheme that sets fixed prices (a tariff) for clinical procedures and activity in the NHS, whereby all trusts are paid the same for equivalent work.

**Practice-based commissioning (PBC)** – PBC gives GPs direct responsibility for managing the funds that the primary care trust has to pay for hospital and other care for the GP practice population.

**Primary intracerebral haemorrhage (PICH)** – Bleeding in the brain caused by the rupture of a blood vessel within the head.

**Quality and Outcomes Framework (QOF)** – Part of the contract primary care trusts have with GPs. It is nationally negotiated and rewards best practice and improving quality.

**Rehabilitation** – Combined and co-ordinated use of medical, social, educational and vocational measures for training or retraining the individual to their highest level of functional ability.

**ROSIER** – Recognition of stroke in the emergency room.

**Royal College of Physicians** – The Royal College of Physicians provides extensive information about the practice of medicine and aims to improve communications in the field.

**Skills for Care** – Skills for Care is responsible for the strategic development of the adult social workforce in England. It supports employers in improving standards of care through training and development, workforce planning and workforce intelligence. Alongside the new Children's Workforce Development Council, it is the English component of Skills for Care and Development, the UK-wide Sector Skills Council for social care, children, and young people.

**Skills for Health** – Skills for Health is the Sector Skills Council for the health sector in the UK, covering all roles and functions within the NHS and the independent sector. It helps the sector develop solutions that deliver a skilled and flexible workforce to improve health and healthcare.

**Supporting People Programme** – A grant programme providing local housing-related support services to help vulnerable people move into or stay independently in their homes.

**Stroke** – A 'brain attack' caused by a disturbance of the blood supply to the brain. See also 'Ischaemic stroke' and 'Haemorrhagic stroke'.

**Transient ischaemic attack (TIA)** – Sometimes also known as a minor stroke, in which symptoms of a stroke subside within 24 hours.

# Annex B

## Key resources



### Connect: The Communication Disability Network

Connect's vision is a world where people with aphasia can find opportunity and fulfilment. They work to promote effective services, new opportunities and a better quality of life for people living with aphasia (communication disability). Their aims are to equip people living with aphasia to reconnect with life again, and to improve services and increase opportunities available for people living with aphasia by changing attitudes and practices in service provision. They aim to increase the ways in which people living with aphasia can be involved in the services and opportunities available to them.

More information about Connect's work, including training for stroke service providers, consultancy, publications and events for people with aphasia, is available from:

Connect, 16–18 Marshalsea Road, London SE1 1HL

Tel: 020 7367 0840

email: [Events@ukconnect.org](mailto:Events@ukconnect.org)

[www.ukconnect.org](http://www.ukconnect.org)

### Different Strokes

Different Strokes is the only national organisation specifically dedicated to the needs of younger individuals affected by stroke. It provides information, advice and rehabilitation services to optimise recovery. Different Strokes was established by a group of younger people affected by stroke, and it is still largely managed and staffed by younger individuals and their family members.

More information on the work of Different Strokes is available from:

Different Strokes Central Services, 9 Canon Harnett Court, Wolverton Mill

Milton Keynes MK12 5NF

Tel: 0845 130 7172

[www.differentstrokes.co.uk](http://www.differentstrokes.co.uk)

## National Service Framework for Older People

The *National Service Framework for Older People*, published in 2001, included a standard that aimed to reduce the incidence of stroke in the population and ensure that those who have had a stroke have prompt access to integrated stroke care services. This has driven forward improvements in stroke care. For example, most trusts that care for people who have had a stroke now have a stroke unit – a rarity just ten years ago. However, there remain issues about capacity and responsiveness, and this is one of the drivers in the development of a stroke strategy.

[www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4003066](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4003066)

## National Service Framework for Long-term Conditions

The *National Service Framework for Long-term Conditions*, published in 2005, aims to promote quality of life and independence for people with long-term neurological conditions by ensuring they receive co-ordinated care and support that is planned around their needs and choices. The National Service Framework does not address individual neurological conditions separately as there are so many elements of service provision that are common to different conditions. It will clearly be important for commissioners to take into account the quality requirements of the National Service Framework when planning services for those affected by stroke who have long-term support and care needs. References to the *National Service Framework for Long-term Conditions* are made throughout this strategy, highlighting where its quality requirements are relevant.

[www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4105361](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4105361)

## National Clinical Guidelines

The *National Clinical Guidelines* were developed by the Intercollegiate Stroke Working Party, co-ordinated by the Clinical Effectiveness and Evaluation Unit (CEEU) of the Royal College of Physicians (2002). The aims of the guidelines are to provide explicit recommendations for practising clinicians, managers, patients and carers about the management of stroke and Transient Ischaemic Attack (TIA), covering the whole care pathway from acute event to longer-term management in the community, based on best available evidence. The second edition was published in September 2004, a supplement on Early Recognition was produced in 2006, and it is expected that a third edition of the full guidelines will be published in 2008.

[www.rcplondon.ac.uk/pubs/books/stroke/](http://www.rcplondon.ac.uk/pubs/books/stroke/)

## Our health, our care, our say

The *Our health, our care, our say* White Paper sets out a vision to provide people with good-quality social care and NHS services in the communities where they live. NHS services are halfway through a ten-year plan to become more responsive to patient needs and prevent ill-health by promoting healthy lifestyles. Social care services are also changing to give service users more independence, choice and control.

## Royal College of Physicians Sentinel Audit

The CEEU conducted the first round of the National Sentinel Stroke Audit in 1998 and four further rounds in 1999–2002, 2004 and 2006. The objective of the Sentinel Audit is to assess the quality of care for people who have had a stroke and to help trusts use audit as a means of quality improvement. The audit is based on evidence-based standards for the organisation of services and process of care, agreed by the representatives of the colleges and professional organisations of the disciplines involved in the management of stroke. This has been an important driver for improvement, as services are able to judge their standards against their own performance and that of others.

[www.rcplondon.ac.uk/college/ceeu/ceeu\\_stroke\\_home.htm](http://www.rcplondon.ac.uk/college/ceeu/ceeu_stroke_home.htm)

## Reducing Brain Damage: Faster access to better stroke care

The National Audit Office published *Reducing Brain Damage: Faster access to better stroke care* in November 2005, recommending further improvements in preventing strokes in the first place, and treating and managing people with stroke. The National Audit Office will review their findings within the lifetime of the current Parliament.

[www.nao.org.uk/pn/05-06/0506452.htm](http://www.nao.org.uk/pn/05-06/0506452.htm)

## Mending Hearts and Brains

The National Director for Heart Disease and Stroke, Professor Roger Boyle, in his report *Mending Hearts and Brains*, published in December 2006, made the clinical case for reconfiguration in terms of delivering better urgent care for heart attack and 'brain attack'. This stressed the need for heart attack and stroke services to be delivered by personnel with an appropriate level of experience and training, in settings with sophisticated diagnostic and monitoring facilities, on a 24 hours a day, 7 days a week immediate access basis.

[www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_063282](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_063282)

## Improving Stroke Services: A Guide for Commissioners

*Improving Stroke Services*, published in December 2006, was designed to help commissioners assess their local need, review how well services are meeting it currently, and identify where to invest in the future. It provided advice on good practice to commissioners, highlighting key issues to consider and summarising supporting resources. It focused on ways to apply the DH commissioning framework to stroke services, highlighting emerging themes from the national strategy in order to support services in planning ahead for implementation.

[www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_063260](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_063260)

## Action on Stroke Services: An Evaluation Toolkit (ASSET) for providers and for commissioners

*Action on Stroke Services: An Evaluation Toolkit (ASSET)* for providers was created to help healthcare organisations improve and transform stroke services for patients. It enables providers to benchmark their performance against the rest of England. It also demonstrates the impact for the particular trust of several key improvements to TIA clinics and acute stroke care in terms of better patient outcomes and reduced lengths of stay. ASSET for commissioners builds on this and shows primary care trusts and GPs, by using their own statistics, how better care – including improved prevention activities – will save money in the long run, reduce hospital bed days, reduce disability, and save lives.

[www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4134498](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4134498)

## Speakability

Speakability was founded in 1979 by a stroke survivor who had aphasia. Since then, it has supported and empowered individuals to rebuild their communication skills and confidence through self-help and greater understanding of language-loss.

More information on Speakability's work is available from:

1 Royal Street, London SE1 7LL

Tel: 020 7261 9572

Email: [speakability@speakability.org.uk](mailto:speakability@speakability.org.uk)

[www.speakability.org.uk](http://www.speakability.org.uk)

## **Delivering Quality and Value Focus on: Acute Stroke**

*Delivering Quality and Value Focus on: Acute Stroke* aims to help local health communities and organisations improve the quality and value of care for acute stroke patients.

This document is part of a series produced by the Delivering Quality and Value team at the NHS Institute for Innovation and Improvement as part of the high-volume Healthcare Resource Groups (HRG) programme.

[www.institute.nhs.uk](http://www.institute.nhs.uk)

## **The National Library for Health – Stroke Specialist Library**

The National Library for Health have commissioned a Stroke Specialist Library to bring together high-quality knowledge on stroke prevention, treatment and rehabilitation, with the aim of helping to mobilise that knowledge so that stroke patients and their families get better care.

[www.library.nhs.uk/stroke](http://www.library.nhs.uk/stroke)

## **Prime Minister's Strategy Unit report – Improving the Life Chances of Disabled People**

The Prime Minister's Strategy Unit published *Improving the Life Chances of Disabled People* in 2005. The report sets out a 20-year strategy with approximately 60 recommendations.

It focuses on independent living, outlining person-centred planning, individual budgets and self assessment, enabling choice and control for disabled people.

[www.cabinetoffice.gov.uk/upload/assets/www.cabinetoffice.gov.uk/strategy/disability.pdf](http://www.cabinetoffice.gov.uk/upload/assets/www.cabinetoffice.gov.uk/strategy/disability.pdf)

## **National Institute for Health Research (NIHR)**

The aim of the National Institute for Health Research is to provide the framework through which DH can position, maintain and manage the health research systems. The National Institute for Health Research (NIHR), funded by the government and other external bodies, provides the NHS in England with the support and infrastructure it needs to conduct research.

[www.nihr.ac.uk](http://www.nihr.ac.uk)

## **The Medical Research Council (MRC)**

The Medical Research Council (MRC) is a publicly funded organisation dedicated to improving health of individuals. They support research across the spectrum of medical sciences, in universities and hospitals, in their own units and in institutes throughout the UK.

[www.mrc.ac.uk/index.htm](http://www.mrc.ac.uk/index.htm)



## The Stroke Association

The Stroke Association is the only UK-based charity solely concerned with combating stroke in people of all ages. It funds research, provides services, campaigns, educates and provides information, acting as a voice for everyone affected by stroke in the UK.

More information on the Stroke Association's work is available from:

Stroke House, 240 City Road, London EC1V 2PR

Tel: 020 7566 0300

Email: [info@stroke.org.uk](mailto:info@stroke.org.uk)

[www.stroke.org.uk](http://www.stroke.org.uk)

## The British Heart Foundation

The British Heart Foundation is an organisation with a vision of a world in which people do not die prematurely of heart disease. It works towards this through pioneering research, prevention activity and by ensuring quality care and support for people living with heart disease.

[www.bhf.org.uk/about\\_us/what\\_we\\_do.aspx](http://www.bhf.org.uk/about_us/what_we_do.aspx)

## Wellcome Trust

The Wellcome Trust's aims are to advance and promote research, with the end result being improving human and animal health.

[www.wellcome.ac.uk/funding/](http://www.wellcome.ac.uk/funding/)

## The Economic and Social Research Council (ESRC)

The Economic and Social Research Council (ESRC) is one of the UK's leading research funding and training agency. ESRC funds research and training in economic and social issues. Their aim is to provide high-quality research on issues of importance to business, the public sector and government.

[www.esrc.ac.uk/ESRCInfoCentre/index.aspx](http://www.esrc.ac.uk/ESRCInfoCentre/index.aspx)

## Payment by Results (PbR)

The aim of Payment by Results (PbR) is to provide a clear, rules-based system for paying trusts. It will reward efficiency, support patient choice and diversity and encourage activity towards sustainable waiting-time reductions. Payment will be linked to activity and adjusted for casemix. Importantly, this system will ensure a fair and consistent basis for hospital funding, rather than being reliant principally on historic budgets and the negotiating skills of individual managers.

[www.dh.gov.uk/en/Policyandguidance/Organisationpolicy/Financeandplanning/NHSFinancialReforms/index.htm](http://www.dh.gov.uk/en/Policyandguidance/Organisationpolicy/Financeandplanning/NHSFinancialReforms/index.htm)

## National Institute for Health and Clinical Excellence (NICE)

The National Institute for Health and Clinical Excellence (NICE) is an independent organisation which aims to provide national guidance on promoting good health and preventing and treating ill-health in the areas of:

- ischaemic stroke (acute) – alteplase;
- hypertension;
- atrial fibrillation;
- cardiovascular disease – statins;
- diabetes;
- smoking;
- obesity (under development);
- stroke and TIA (under development); and
- vascular disease – clopidogrel and dipyridamole.

[www.nice.org.uk](http://www.nice.org.uk)

## Royal College of Physicians

The Royal College of Physicians is a registered charity that promotes high-quality care for patients by encouraging the highest standards of medical practice. It provides and sets standards in clinical practice and education and training, conducts assessments and examinations, quality assures external audit programmes, supports doctors in their practice of medicine, and advises the Government, public and the profession on health care issues including:

- primary care concise guidelines for stroke;
- recognition and emergency management of suspected stroke and TIA; and
- National Clinical Guidelines for stroke.

[www.rcplondon.ac.uk/college](http://www.rcplondon.ac.uk/college)

## Joint British Societies (JBS)

The aim of the Joint British Societies is to promote a consistent multidisciplinary approach to the management of people with cardiovascular disease:

Guidelines on prevention of cardiovascular disease in clinical practice are available from:

[www.bcs.com/download/651/JBS2final.pdf](http://www.bcs.com/download/651/JBS2final.pdf)

## British Hypertension Society (BHS)

The British Hypertension Society provides a medical and scientific research forum to enable sharing of cutting-edge research in order to understand the origin of high blood pressure and improve its treatment:

Guidelines for management of hypertension are available from:

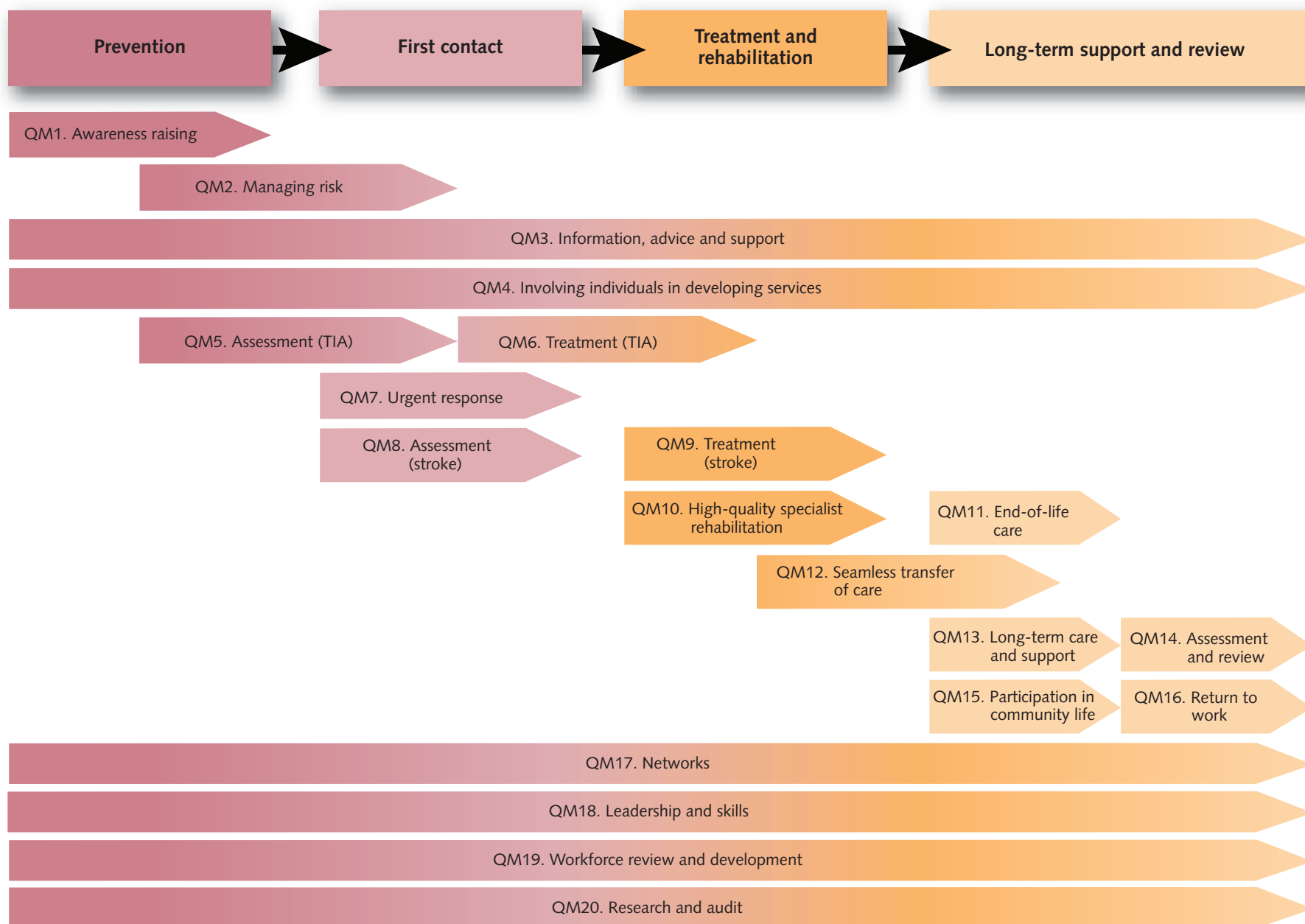
[www.bhsoc.org/default.stm](http://www.bhsoc.org/default.stm)

## Creating Sustainable Communities: Supporting Independence

In June 2007 Communities and Local Government published a strategy for the future of the Supporting People programme. The strategy sets out their plans to:

- ensure that service users are kept at the heart of the programme;
- increase the support to service providers, including helping all providers to complete fairly for contracts to deliver services; and
- give greater freedom and support to local authorities to make Supporting People work well in their area.

[www.spkweb.org.uk/Subjects/Supporting+People+Strategy+-+DCLG/Creating+Sustainable+Communities+-+Supporting+Independence.htm](http://www.spkweb.org.uk/Subjects/Supporting+People+Strategy+-+DCLG/Creating+Sustainable+Communities+-+Supporting+Independence.htm)



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